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COMMUNITY PASTORAL CARE IN FAITH AND LIGHT

A Qualitative Study of Perpetual Parenthood from a Pastoral Care and Counselling Perspective

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THESIS

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ABSTRACT

Faith and Light is a Christian community that exists for people with an intellectual disability, their families and their friends, and that meets monthly to reflect on Scripture, to pray and to celebrate together. It promotes presence to one another and friendship amongst its members. This ethnographic study explored how parents from a local community experienced the "launching" phase of the family life cycle. Analysis of data from focus groups, from participant observation as a chaplain, and from informal interviews revealed particular aspects of parents experiences, including: challenges parents face, particularly with regard abuse and the need to advocate; concerns over the adequacy of care their offspring receive; the impact of the various life cycle transitions; and their investment in their offspring and peculiar knowledge of them. I suggest that a phenomenon of "perpetual parenthood" undergirds these themes: parents understand their responsibilities for their offspring with an intellectual disability as being life-long, such that launching may never occur. A central existential ambivalence for these parents is that of holding on versus letting go, where parents discover and create their own provisional balance in the dilemma. Parents identified several attributes of Faith and Light's community life that were helpful to them (mutual support and understanding, interaction, welcome and friendship), and to their offspring (revealing their beauty and giftedness, growth and friendship, Christian formation, listening and acceptance). Faith and Light's provision of care to parent members models aspects of "a *theological* pastoral care and counselling." This approach locates pastoral care and counselling ecclesially, and proposes an asymmetrical relationship between the disciplines of theology and related social sciences, where the pastoral carer, working within an explicitly Christian metanarrative, has recourse to insights from related secular disciplines on an ad hoc basis. The study concludes with an exploration of how, on the basis of this relationship, the three foci of enquiry, namely Faith and Light, the phenomenon of perpetual parenthood, and a theological pastoral care and counselling, might inform each other.

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To Sandy and Sue, my parents,
and to Marie-Hélène Mathieu and Jean Vanier, parents of Faith and Light

Chapter One

INTRODUCTION

It was while working as a live-in assistant with a L'Arche community (a Christian residential community centred around people with an intellectual disability) from 1993 to 1995 in France that I wondered whether what was being lived in this particular context had implications beyond Christian residential community. Put simply, it seemed to me that the manner in which these people were living the Christian Gospel could benefit relational dynamics (amongst other things) in other settings. I was particularly interested in the influence of the theology, spirituality and ethos of the L'Arche movement on family functioning. The question remained as to what such an influence might look like and how one might assess and evaluate it. It was some years later that I discovered the sister organisation to L'Arche called Faith and Light. Briefly, Faith and Light is an organisation that issues from the same root stock as L'Arche, sharing a co-founder in the person of Jean Vanier. His thought has been fundamental in shaping the theology, spirituality and ethos of both communities. Faith and Light distinguishes itself from its sibling by being non-residential. Rather, it is comprised of local Christian communities that exist to support people with an intellectual disability, their parents and their friends through meeting together on a monthly basis for sharing, prayer and celebration. It promotes fidelity to friendships between meetings. As I became better acquainted with the Faith and Light movement as a chaplain, it seemed that this organisation might provide a better fit for exploring the influence of the theology, spirituality and ethos of L'Arche/Faith and Light on families. Various members of families attended the meetings on a regular basis and I wondered whether it might be possible to elicit from them how contact with Faith and Light had impacted on their family life. The task now became how to organise and limit the study. After consulting with my supervisor, I cast the research project as an ethnographic study and defined its locus in three ways. First, I chose to limit the study to members of one local Faith and Light community. Different local communities could have different emphases in their meetings and therefore play different

roles in the lives of its member families. Second, I decided to interview parents only, as the architects of the family system. It seemed the parent subgroup would be best placed to identify and articulate ways in which Faith and Light had influenced the family as a whole. Third, I narrowed the focus of the study to one particular stage in the life cycle of the family, that of launching children.[1] Rather than expecting parents to survey family functioning generally since coming to Faith and Light, I invited them to concentrate on one phase (and that popularly recognised as being the most stressful) in order to determine whether Faith and Light, its theology, spirituality and ethos, had had any discernible influence in how they managed the transition. Therefore, the research question evolved as "What are the contributions of Faith and Light to families with offspring with an intellectual disability at the launching or transition phase?"

The discipline within which the question is cast is pastoral care and counselling. Hence, of particular interest was Faith and Light's role as a provider of pastoral care and counselling to these families at a particular phase in their family life cycle. Faith and Light is a Christian community that seeks to provide support to people with an intellectual disability, their families and their friends. To what extent (if any) do parents experience support in their family life from Faith and Light? How do they experience it? Could the support mentioned be deemed to be *pastoral*? If so, what does the praxis of Faith and Light have to offer to the discipline of pastoral care and counselling? Conversely, what does the theory and practice of pastoral care and counselling have to offer Faith and Light in its interpretation and delivery of pastoral care? These were some of the guiding questions through the research process. This research project was carried out on the basis of a widely accepted model of pastoral care, which emphasised insights from a perspective of social sciences. The progress of the study was matched in some ways by my increasing concern that Faith and Light needed to apprise itself with, and avail itself of, more sophisticated techniques of pastoral care in order to respond more sensitively and meaningfully to its members. It seemed to me that this was an organisation implicitly, if not explicitly, extending pastoral care to its members. Yet it

[1] *Launching* describes the phase in the family life cycle when children leave the family home. It is one of "many life cycle tasks that must be accomplished during the midlife years" (Blacker, 1999, p. 287).

had no apparent recourse to any insights from the social sciences which inform the field. In the course of compiling the research findings I began to entertain theological questions about the nature of pastoral care and counselling. The tensive relationship in the practice of pastoral care and counselling between theology and the social sciences became more apparent. The longer I have travelled with the community, the more I have come to appreciate the genius of the movement and the understanding of the Christian ministry of pastoral care and counselling that it has received and developed. The concerns that were accumulating as I viewed the organisation of Faith and Light and its delivery of care from a predominantly social scientific explanatory schema, were diminished in rediscovering and reclaiming the theological and ecclesial identity and location of pastoral care. The care that Faith and Light extended to its members, and which parents identified and articulated, made sense when the primacy of the theological and ecclesial nature of pastoral care and counselling was re-established.

Therefore, I begin in the first chapter by laying out some of the theological questions that have preoccupied me in this research project with particular emphasis on the relationship between theology and the social sciences, and theology and experience in the field of pastoral care and counselling. I argue for a *theological* pastoral care and counselling, encompassing a retrieval and a revival of its theological and ecclesial heritage. I advance support for this shift from other fields of knowledge in which an asymmetrical relationship between theology and a related discipline has been advocated. Such a move is not intended to dismiss or diminish insights from the social sciences. Indeed this knowledge will provide for a more nuanced provision of care in specific instances. However, I accord primacy to pastoral care and counselling's theological and ecclesial nature and identity, and annex insights from the social sciences on an ad hoc basis. I expound upon a narrative hermeneutic and Lindbeck's concept of "intratextuality" as that which grounds an understanding of the interplay between the story of Faith and Light and the stories of parents.

In the second chapter I trace the history and development of the Faith and Light movement, and sketch some of its theological motifs and the features of its spiritual

practice. In the third chapter I review family systems literature, relevant to the reported experience of parents. The theories and perspectives surveyed include: family systems theory; individual, family and intellectual disability life cycles with particular reference to Rolland's Family Systems Illness Model; a competence or resource-based perspective; the launching phase; stress and coping theory; grief theory; and family belief systems theory. These theories provide a systemic and developmental schema from a social science perspective that serves to explicate particular aspects of parents' reported experience. The asymmetrical relationship between theology and social sciences in a theological pastoral care and counselling will be recalled, where insights from the related secular disciplines are annexed to Christian theological explanatory schema on an ad hoc basis. That is to say, the aforementioned theories find their place within an explicitly Christian metanarrative, which includes a Christian theological anthropology.

Part of the research project involved exploring the experiential world of parents around launching in a Faith and Light community. Because the inquiry was "discovery-oriented" with a focus on process and meaning, a qualitative methodology proved a good fit (Sprenkle & Moon, 1996, p. 5). In the fourth chapter I describe ethnography as the type of qualitative methodology chosen because of my interest in the "insider's" experience. I outline the use of focus groups as the primary ethnographic technique for gathering data, together with the techniques of participant observation and open-ended interviews. I summarise the means used to collect, reduce, code and analyse the data generated from focus group discussions, participant/observation and the informal interviews.

In the fifth chapter I present a description of findings from the ethnographic study of parents' experience based primarily on data from focus group discussions, and supplemented with data from participant/observation and informal interviews. I have arranged the findings thematically, weighted according to the number of lines of transcript that participants devoted to discussion of the identified themes. Parents spoke most often of the particular challenges they faced: primarily the threat of abuse and the need to advocate. In decreasing order of importance parents articulated their thoughts and feelings on six further themes: their concerns around caregiving and their experience of

health care professionals; Faith and Light and its impact on them as parents and on their offspring; their responses to transitions, including the attendant pain and ambiguity; their recollections from the earlier years of their offspring; their devotion to their daughters and sons; and finally those lessons they had learned from their offspring.

The data generated divided the research question into two distinct parts: first, the experiential world of parents as they faced launching their offspring with an intellectual disability; and second, the role of Faith and Light as a provider of pastoral care and counselling in that context. In the sixth chapter I explore further the first part, the parents' experiential world, suggesting an organising concept that underlies the seven themes identified in the previous chapter. In listening to these parents from a Faith and Light community discuss their experiences with particular reference to the launching phase in the family life cycle, it seemed that they saw themselves as *parents in perpetuity*. I have coined the term *perpetual parenthood* to describe the phenomenon. It appeared that holding on and letting go was a central ambivalence in the lives of these parents, with each set of parents striking their own provisional balance in the dilemma. There were different outworkings of the balance for each set of parents, and the balance shifted over time. What seemed to unite these parents was the deep sense of responsibility they continued to have for their offspring whether they remained in the family home or not. I identify other themes outlined in Chapter Five that appear to be consistent with the phenomenon of perpetual parenthood: the challenges parents face, particularly around the threat of abuse and the need to advocate for their offspring; their concerns over the adequacy of care their offspring receive from caregivers and health care professionals; the impact of the various transitions across the life cycle for parents and offspring alike; and parents' investment in their offspring and their peculiar knowledge of them. In the second part of the chapter I relate the identified phenomenon of perpetual parenthood to relevant theory from family systems literature. The related social scientific theory that might assist to explicate further the phenomenon of perpetual parenthood include: a systemic perspective outlining the biophysical, psychosocial and spiritual-vocational dimensions in family life; Bowlby's attachment theory; Boszormenyi-Nagy's concept of relational ethics and asymmetrical parent-child relations; Ricoeur's narrative theory and

re-storying; grief theory and the concept of relocation. I conclude with a pastoral theological perspective on leaving home, with suggestions for the use of ritual.

In the seventh chapter I clarify the three main avenues of enquiry in this research paper: an approach to pastoral care that I have termed *theological pastoral care and counselling*; the theology, spirituality and ethos of the Faith and Light movement; and the phenomenon of perpetual parenthood among parents of offspring with an intellectual disability and the accompanying holding on/letting go existential ambivalence. The chapter proceeds to explore how these three foci might inform each other. What implications do theological pastoral care and counselling, the community of Faith and Light, and the concept of perpetual parenthood have for one another? How might each contribute to an understanding of the others? I organise the enquiry around three questions.

1. How do perpetual parenthood and Faith and Light inform each other?
2. How do perpetual parenthood and theological pastoral care and counselling inform each other?
3. How do theological pastoral care and counselling and Faith and Light inform each other?

I return to the thoughts expressed in the opening chapter regarding the theological and ecclesial nature and identity of pastoral care and counselling, and the asymmetrical relationship between theology and the social sciences, and theology and experience. From this position I evaluate Faith and Light's contribution to the paradigm of pastoral care and counselling, including the theology underwriting it, in other settings. At the same time it is important to recall that theology is not an inert body of knowledge waiting to be acted upon by L'Arche/Faith and Light. Theology will have questions to put to Faith and Light. I explore what kind of critical reception Faith and Light might expect in the life of the Church. In the concluding chapter, I address the limitations of the research and point out directions for future research.

I turn now to the trace the academic context within which the contribution of Faith and Light to family life is being explored: namely, a *theological* pastoral care and counselling.

Chapter Two

ACADEMIC CONTEXT – A THEOLOGICAL PASTORAL CARE AND COUNSELLING

Introduction

The field of pastoral care and counselling provides the landscape against which this study is framed. Specifically, the research explores how pastoral care and counselling measures and is measured by what happens in a local Faith and Light community with particular reference to the reflections of a small group of member parents.

I commence the enquiry by outlining briefly the field of pastoral care and counselling, and identifying a current trend that promotes the faith community locale of the field's interpretation and delivery. I continue by advancing an approach, which I have named *theological pastoral care and counselling*, aimed at redressing what appears to be an imbalance in the North American Protestant context. The chapter sketches some of the defining features of this proposed approach.

From the outset, I signal that I write from the perspective of a professional religious in the Anglican Church, where pastoral care has a recognised heritage. In the Anglican tradition, Anglican clergy in Post-Reformation England emphasised the tasks of preaching and pastoral care.[2]

[2] It is important to note that Anglicanism historically has favoured tradition over experience in its construal of pastoral care and counselling (Mills, 1990, p. 841).

Some Definitions

It may be helpful to clarify the common meaning of some of the terms used in the field, before offering a critique. I use the definitions of *pastoral* and *care* given in *Dictionary of pastoral care and counseling* (Hunter, 1990). Pastoral care derives from the biblical image of a shepherd, and connotes "solicitous concern expressed in religious community for persons in trouble or distress" (Mills, 1990, p. 836). It arises out of the tradition of the "cure-of-souls," where "cure" bore the sense of carefulness or anxious concern (and not necessarily healing), and "souls" referred to the animating centre of personal life and seat of relatedness to God.[3] It is generally recognised that the content of care includes the pastoral functions of healing, sustaining, guiding and reconciling (e.g., Hiltner, 1949, 1958; Clebsch & Jaekle, 1964). Oates (1990, p. 832-834) outlines the neo-traditional methods or classical forms of pastoral care: scriptural instruction, interpretation, proclamation; preaching as pastoral care; pastoral use of initiative; and prayer, contemplation, meditation and spiritual direction. In keeping with the tenor of recent writers I use the generic term *pastoral care and counselling* to describe the field of pastoral care and pastoral counselling.[4]

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[3] It is important to make two further clarifications: first, the term *pastoral* refers to the person of the religious leader *or* the motivation of caregiver reflecting the values of community; second, the term *care* connotes any pastoral act motivated by a sincere devotion to the well-being of others *or* the communication with persons or groups seeking interpersonal, moral or spiritual guidance. Mills (1990, p. 836) summarises by saying that pastoral care is concerned with humankind's relatedness to God and that which facilitates or impedes such relatedness.

[4] O'Connor (2003) notes that the separation between pastoral care and pastoral counselling began in the United States after the First World War. Prior to the 20th century, there was no distinction. The single term *cure of souls* covered the field. In the United States, pastoral care is often associated with chaplaincy, the Association for Clinical Pastoral Education (ACPE), and the Boston approach; pastoral counselling is often associated with the American Association of Pastoral Counselors (AAPC) and the New York approach. In Canada both camps come together under the umbrella of the Canadian Association of Pastoral Practice and Education (CAPPE). Many contemporary writers see a difference between the two, classifying pastoral counselling as a specialised form of pastoral care, requiring specialised education and training. However, according to O'Connor, more recent literature has downplayed the differences, and a number of authors (e.g. Gerkin, 1997; Pattison, 1969; Oden, 1989; Hunsinger, 1995; Glaz and Moessner, 1991; and Stone, 1994) see no reason for a division. I refer the reader to Dr. Tom O'Connor's (2003) comprehensive survey and assessment of the relevant literature in his article "Pastoral counselling and pastoral care: Is there a difference?" I agree with his finding that the difference is merely one of emphasis and expression. Hence I use the term "pastoral care and counselling."

Historical Schema and Recent Developments

Academics have proposed various schema to trace the history and development of pastoral care and counselling.[5] Gerkin (1997) for example posits that each historical era has emphasised one of the four pastoral functions (healing, sustaining, guiding, reconciling), depending upon the prevailing perspective of the Church and society. Most recently the function of guidance has dominated through the psychotherapeutic paradigm. Patton (1993) distinguishes three major paradigms in the history of pastoral care and counselling: classical, which emphasises the *message* of pastoral care; clinical pastoral, which focuses on the *person* in the giving and receiving of care; communal contextual, which recognises care as a ministry of the *faith community*, with the *context* influencing both the message and the people involved. While he casts the contemporary paradigm as communal contextual, he argues that pastoral care and counselling need attend to all three historical paradigms.

Whichever schema that academics in the field have used, there seems to be a consensus that in the twentieth century psychological and social sciences have constituted the major influence in pastoral care and counselling in the North American Protestant tradition, and have come to dominate theological understandings. Psychological theories such as the secular humanism of Carl Rogers have reinterpreted the theory and practice of pastoral care and counselling. Tillich's method of correlation[6] has allowed his understanding of the Gospel as God's acceptance of humankind in spite of their unacceptability to be linked with Roger's clinical stance of "unconditional positive regard." This confluence of ideas has been highly influential in the evolution of the field. Holifield (1990, p. 514) notes the resurgence of interest in pastoral care since the Second World War. He argues

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[5] For other useful discussions on the history and development of pastoral care and counselling in North America from a Roman Catholic and a Protestant perspective, see the entries of Holifield (1990), Champlin (1990), MacLauchlan (1990), Vissher (1990), and Oates (1990) in *Dictionary of pastoral care and counseling* edited by Rodney Hunter (1990).

[6] Holifield (1983) argues that Tillich's method of correlation has been one of the most important contributions to the pastoral care tradition. Tillich correlates questions arising from the psychological or philosophical analysis of existence with theological answers from Christian tradition. His method allowed him to perceive the resonances between psychological language and theological categories. Gerkin (1997) notes that pastoral care in the North American Protestant tradition has generally preferred Tillich's "existential neo-orthodoxy" to Barth's "radical transcendentalism."

that humanist growth psychologies (as propounded by Clinebell and Johnson) have taken the field beyond Rogerian counselling, and that a preoccupation with counselling has distorted the understanding of pastoral care. He observes that the goalposts of pastoral care and counselling have shifted from the theological notion of salvation to the cultural ideal of self-actualisation. Personal growth and fulfilment have been a focus. Gerkin (1997) identifies the multiplication of developments by secular helping professions during the 1970s and 1980s, agreeing that the focus on psychologically informed diagnosis and interventions has overlooked the theological grounding of pastoral care. Discipline, confrontation and normative theological judgment, legitimate aspects of the field in the past, have received less attention in the twentieth century (Mills, 1990, p. 843).[7]

A Future Direction

Clinebell (1990, p. 857) flags the development of the theological, ecclesiological, ethical context of pastoral care and counselling as one of the present trends and future directions for the field.[8] Other voices have sought to reclaim its theological and ecclesial moorings.[9] For example, Gerkin (1997) in a chapter entitled "New directions in pastoral care" calls for a "rediscovery of congregation as primary context and agent of care for the people of God" (p. 92).[10] He cites research showing that the basic matrix of care is communicated in informal, relationally casual ways. He underscores the importance of liturgical practices in expressing God's care for people, recognising that "the power of ritual

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[7] Browning is a strong proponent of the moral dimension implicit in the provision of pastoral care and counselling. For example, in his book written in 1976, *The moral context of pastoral care*, he contends that the erosion of a consensual moral context has meant that the primary issues of morality and ethics need be addressed in pastoral care relationship itself.

[8] It is important to note that the recovery of the faith community dimension to pastoral care and counselling is only one proposed direction. Insights from marginal voices, such as Black and feminist theologians, also challenge the field, emphasising the task of social transformation.

[9] See among others: Browning (1976), Capps (1984), Farley (1982), Gerkin, (1997), Lapsley (1992), Patton (1993), and Poling (1985).

[10] Of course, there are other directions Gerkin indicates: the pastor as prophet, priest and wise guide, as shepherd of the flock, as mediator and reconciler, as ritualistic leader; and pastoral care as attending to moral life, as discerning the work of the Spirit, as listening to the inner life of people, as attending to those with special needs, as addressing social situations, and as playing an educative role.

actions to communicate care is greatly dependent upon the informal atmosphere of care within the community that surrounds those actions" (p. 94).

In a recent review of pastoral counselling theorists, Stone (2001) observes that pastoral counselling literature is oriented to pastoral counselling specialists and pastoral theologians with a significant long-term individual therapy bias that ignores the context of faith community. "A dated, embedded theological anthropology and etiology in psychoanalytic thought (that has slipped from dominance in contemporary psychology and theology) persists in pastoral theology" (2001, p. 188). He argues for a renewal of pastoral care and counselling's ecclesial location, citing William Hulme (1981) who wrote that "the congregation as a local community of faith is the most unused, undeveloped, and unorganised of all of the unique resources of the pastoral counsellor" (p. 153).[11]

Theology – Practical and Pastoral

I turn from an outline of pastoral care and counselling to consider the branch of theology which underwrites it – practical theology and the subcategory of pastoral theology. Practical theology is first and foremost *theology.* It derives from the collective wisdom and teachings of the Church over two thousand years. The fact that one places an adjective in front of theology does not change the fundamental nature of the discipline. Practical theology distinguishes itself from biblical, dogmatic, systematic and historical theology on the grounds that it reflects upon the being and activity of the Church in the world.[12] Its subject matter appears to warrant its own particular methodology.[13] Generally

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[11] Hulme (1981, p. 153) cites Eduard Thurneysen's definition of pastoral counselling as "an *extra*-ordinary ministry, dependent for its function in the church on the ordinary ministries." Stone (2001, p. 187) lists other authors who support the parish context of pastoral care and counselling: Brister, Clinebell, Hulme, Kemp, Oates, Switzer, and Taylor. In particular, Oates, Kemp and Clinebell contend that the congregational context of pastoral counselling is vital.

[12] This seems to be the consensus position of both Protestant and Roman Catholic pastoral theologians from a survey of entries in the *Dictionary of pastoral care and counseling.* Browning (1983) regards practical theology as a substantive theological discipline, with own methodology, involving reflection on church's life in world as a whole. It is not limited to reflections on functions of the clergy. Kinast (1990, p. 873) defines practical theology as a theological analysis of the total social situation in which the Church finds itself, in order to plan for the enactment of the Church's nature in that precise social situation. Farley (1990,

speaking, pastoral theology is recognised as a subcategory of practical theology concerned with studies related to pastoral care.[14] Kinast (1990, p. 873) defines pastoral theology as the "use of *theological sources* [italics added] to ground, interpret, and guide the activity that constitutes the pastoral life of the church." He defines the theology underwriting pastoral practice in general terms, without limiting the sources that may be called upon.[15]

Farley (1990, p. 935) makes the valid point that when practical theology construes itself as independent of other theological disciplines (such as biblical, systematic/dogmatic, or historical) it may see itself as no longer subject to the overarching theology of church and ministry. One of the consequences of this separation is that each of subcategories within practical theology (which includes preaching, liturgics, catechetics, church polity and pastoral care and counselling) risks becoming merely skill-based. The auxiliary discipline associated with each subcategory of practical theology (psychology in the case of pastoral

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p. 934) offers three definitions: (1) the field of study in clergy education consisting of preaching, liturgics, pastoral care, catechetics, and church polity and administration; (2) the discipline in clergy education concerned with contemporary life and activity of church; and (3) the discipline of theology concerned with individual and corporate Christian practice in contemporary situation. He notes that more recently practical theology has tended to cover all disciplines of church or ministerial activity.

[13] Farley (1990, p. 934) states that practical theology has become a way of doing theology, a mode of theological thinking focussed on situation, event, or practice rather than a text or a symbol. I question the usefulness of this distinction.

[14] Burck and Hunter (1990, p. 867) draw a distinction between two definitions of pastoral theology: (1) a practical theological discipline concerned with theory and practice of pastoral care and counselling (theology *of* pastoral care); (2) a form of theological reflection in which pastoral experience serves as the context for critical development of basic theological understanding (doing theology *pastorally*). In other words they distinguish between pastoral theology as a branch of ecclesiology or ethics (applying theology to pastoral situations) and pastoral theology as a way of doing theology contextually, out of a pastoral situation, with a pastoral perspective.

[15] It is beyond the scope of this paper to pursue further the definitions given. I would note that some of the distinctions drawn between pastoral theology and other categories of theology appear arbitrary. The classic definition of Hiltner distinguishes the "operation-centred" nature of pastoral theology from that of the "logic-centred" classical theology as

> that branch of theological knowledge and inquiry that brings the shepherding perspective to bear upon all operations and functions of the church and the minister, and then draws conclusions of a theological order from reflection on these observations (Hiltner, 1958, p. 20)

It might be that Hiltner is basing his understanding of "classical" theology on post-Enlightenment liberal Protestant theology. My hope is that *all* theology is ecclesially located, and could therefore be termed "operation-centred" rather than "logic-centred." Browning (1983) differentiates between systematic theology and pastoral theology on the grounds that the former articulates and develops *general* meanings, whereas the latter concerns itself with *normative* meanings and principles. It is probable that some systematic theology includes an ethical dimension rendering some of its meanings normative, just as it is probable that some pastoral theology does not necessarily develop normative meanings.

care and counselling) may dominate, determining both the form and content of the field. In this sense psychology and related social sciences come to set and to drive the agenda in pastoral care and counselling.

This is one of the reasons that the full ambit of the Church's theological resources need be available to the field of pastoral care and counselling. The division of the discipline of theology into the categories of biblical, systematic/dogmatic, historical and practical does not change the fundamental nature of the activity. Practical theology (and hence pastoral theology) is first and foremost theology. Practical theology is derivative of its forebears, and needs at once to be biblical, systematic/dogmatic and historical. With practical theology's particular attention to context, the nature of the relationship of theology to the context will need to be clarified. Methodology in practical theology becomes an important consideration. One of the challenges for practical theology is to articulate and develop the *content* of theology at the same time as it wrestles with methodological questions. Jeffery Stout (1988) has stated that preoccupation with theological method is like clearing one's throat. One risks losing one's audience. In practical theology theological method *and* theological content need attention. I propose to explore briefly both dimensions in this chapter.

Setting the Theological Context

Where one chooses to begin in theology determines the content and the outcome of theology (Jinkins, 2001, p. 43).[16] I write from a perspective that locates theology first and foremost in the Trinitarian self-manifestation of God in the person of Jesus Christ. Theology serves the exegesis of Scripture, which bears witness to the nature and activity of God in Jesus Christ.

There is a tendency in the discipline of pastoral care and counselling to look for resources which are or may be extrinsic to the theology which underwrites the care. It can happen

[16] He adds, *" the questions we raise and the way we go about asking those questions largely determine the answers we get"* (p. 43) [italics Jinkins'].

in several ways. For example, one might engage with secular disciplines in such a way simply to supplant theology; or one might engage in a systematic correlation of theological categories with categories of secular pastoral care and counselling. The result of both moves is the opening of the gulf between pastoral care understood as a Church discipline and pastoral care understood as a purely secular discipline. The corollary of the latter instance is that one risks neglecting resources for pastoral care latent within the Church's Scriptural, doctrinal and theological tradition, including its sacramental life.

What would the practice of pastoral care look like if it were more fully grounded in the ecclesial context in which Scripture, doctrine and tradition function? What would happen if the Church, without ignoring insights from secular disciplines, looked first to its own wisdom and practice, and sought not to locate its own tradition of pastoral care within a secular explanatory schema? There are voices within the North American context as indicated above that suggest that not only is this possible, but that it may be desirable to relocate and even to sequester pastoral care and counselling within an ecclesial context.

The Ecclesial Location of Pastoral Care and Counselling

The ecclesial location of pastoral care and counselling is premised upon the response to a prior question. If one makes the assumption that pastoral care and counselling broadly speaking is an act of attentiveness to others, why should one give attention to another? A response is to have recourse to incarnational and soteriological categories. At the heart of the Gospel is the truth that God in Jesus Christ attends to humankind. Therefore, if one grounds pastoral care biblically, then the practical outworking of care finds exemplification in the portrayal of Jesus Christ in the Gospels. There it is shown that even when he has "set his face" for Jerusalem, knowing all that is to befall him, he still practices an attentiveness to people, that is itself salvific. Pastoral care needs to be an embodiment of the Gospel. Attentiveness in pastoral care is an embodiment of the love of God in Jesus Christ that lies at the heart of the Gospel.

Pastoral care is sourced in the life, death and resurrection of Jesus Christ and all that those dimensions say about the divine reality. Orthodox Christian ecclesiology since Ignatius of Antioch in the first century holds that wherever Jesus Christ is, there is the Church. Life in Christ is Church life. Therefore I understand pastoral care and counselling in concert with those wanting to reclaim the primacy of its ecclesial location. It is a ministry of the Church, and more concretely of the local and visible faith community. It is an incarnation of the ministry of its chief pastor and shepherd Jesus Christ. It finds its legitimation in being sourced in, sustained by and exercised from the context of the gathered people of God, a community of Scripture and the Spirit.[17] Pastoral care, as with all aspects of Christian ministry, is both formed and informed by Holy Scripture and the sacramental life of the Church.

If the context for the understanding and practice of pastoral care and counselling is ecclesial, then one needs to identify the ecclesiological reality as fundamentally Trinitarian. Everything that happens in the economy of salvation is an outflowing in time of God's activity *in se.* In the immanent Trinity, there is complete self-surrender of the Son in love to the divine love of the Father and an outflowing of the same divine love through the Spirit. It is axiomatic to locate human action within the prior and infinitely larger account of divine action. This reflects the overwhelming weight of orthodox 20th century theology, where for example Barth and Rahner have argued for and spearheaded a retrieval of a full-blown Trinitarian theology as the way ahead for Christian thought. In firmly rooting pastoral care and counselling in a Trinitarian category, the field comes into line with the major perduring influence of twentieth century theology. By implication, both Christology and pneumatology become essential doctrines for the understanding of the ministry of pastoral care and counselling. Therefore, pastoral care and counselling is sourced in the paschal mystery of Jesus who spoke, taught and enacted the reign of God in people's lives, bringing healing and salvation to those who would receive him. Jesus' life, death and resurrection continues to chasten the Church, relieving it of its triumphalist

[17] I define a sacrament as a visible, tangible and material extension of Scripture. Word and sacrament are external means of mediating God's being and activity; the Spirit is an internal means of mediating the same. The Spirit is the mediator between Christ and humankind. The Spirit mediates the grace in which, by which and through which pastoral care is administered.

manifestations, and promoting loving service of others. Moreover Jesus' ministry was, and continues to be effected in the power of Holy Spirit. It was not simply a binitarian relationship of Father and Son, but one that was fully Trinitarian of Father, Son and Holy Spirit. It is the Holy Spirit that mediates to humankind the relationship of perfect trust and dependence on God the Father that epitomised Jesus' life on earth (Eph. 2, 4).[18] Christology and pneumatology are fundamental to the understanding and practice of pastoral care and counselling.

Faith and Light's Position to and with the Church

One further point requires clarification. The exploration of pastoral care and counselling in this study occurs within the context of a Faith and Light community. If the location of pastoral care and counselling is primarily ecclesial, the question therefore arises, "What is the relationship of Faith and Light to the Church?"

Article 19 of the Anglican *Thirty-nine Articles of Religion* reads,

> The visible Church of Christ is a congregation of faithful men, in which the pure Word of God is preached, and the Sacraments be duly administered according to Christ's ordinance in all those things that of necessity are requisite to the same.

This article resonates with Article 7 of the Augsburg Confession and Book IV of Calvin's *Institutes.* It connotes the idea of the church as a "visible" place where people are gathered around the preached Word and the celebration of the Sacraments. Church is a place organized for and rooted in worship, prayer, the preaching of the gospel, study of scripture, faithful reception of the sacraments and service to those in need.

The primary way the Church offers care is through Word and sacrament issuing in acts of service and care. Anglicans profess in their creedal formularies (one of which is the Nicene Creed) their belief in "one holy catholic and apostolic Church." Church is both one and pluriform. Faith and Light is a community of support that seeks to integrate itself

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[18] See for example Torrance, J. (1996). *Worship, community and the Triune God of grace: The Didsbury lectures.* Carlyle, UK: Paternoster. Cited in Jinkins (2001, p. 130).

with a local faith community. It is a movement that lays hold of Jesus Christ through the power of the Spirit. It is a microcosm of the Church, an instantiation of the extension of the ministry of Word and sacrament issuing in service of others. Therefore Faith and Light is an extension of the Church life, rather than being co-existent with the Church.

There are further considerations that will require exploration, if one locates pastoral care and counselling in the ecclesial context in which theology functions: namely the relationship between theology and social sciences, and between theology and experience. It is to these relationships I now turn.

Relationship Between Theology and Social Sciences

Historically the field of pastoral care and counselling has straddled Christianity and the surrounding culture, sourcing itself in the teachings and the tradition of the Church, and in the historical, social and political context (including secular bodies of knowledge) (Mills, 1990, p. 837).[19] More specifically one of the principal tensions in the field is the relationship between Christian tradition and related secular disciplines. In the outworking of the balance there will be both benefits and costs to pastoral care and counselling's recourse to related secular disciplines.

One of the benefits of the liaison is an increased understanding of psychological and social phenomena that bear upon humanity and its relationship with God. In addition, pastoral care and counselling and its related secular disciplines have become less dogmatic and judgmental in their approaches, and more relational and compassionate. On the cost side in the field of pastoral care and counselling there has been an uncritical appropriation of some of the ideologies of the social sciences without recognition of the resulting imbalance. For example, emphasis on the immanent has overshadowed the transcendental dimension, the irony being that where one neglects the transcendent, one fails to appropriate fully the immanent. Pastoral care and counselling has come to rely

[19] Mills (1990) notes that there have been comparatively few attempts to trace the history of pastoral care. See McNeill (1951), Clebsch and Jaekle (1964), Kemp (1947), and to a lesser extent Oden (1983) and Hiltner (1958).

heavily on social scientific models without regard for their inherent methodological bias. There has been insufficient attention given to the nature of the relationship between the Christian perspective and the perspective of social sciences on human existence. The effectiveness of personal encounter in all situations in pastoral care and counselling has probably been overrated, and the distinct skills of pastoral conversation and psychotherapy have become confused. The ecclesial and theological resources in pastoral care and counselling have receded in importance, and the theological concept of "kerygmatic specificity" and the role of faith has been diminished (Vissher, 1990, pp. 515-517).

One of the risks for pastoral care and counselling is that it seeks to retain its credibility in the eyes of secular disciplines by adopting their epistemology, and their anthropology of enquiry.[20] John Webster, a prominent Anglican theologian, argues that Christian theology in general has been particularly affected by "standardisation of discourse" prevalent amongst the humanities in modernity.[21] It is both the expansion of particular academic practices, sourced in an "universalist anthropology of enquiry" and the decline in use of theological doctrine in doing theology that has impacted upon the field of pastoral care and counselling. Perhaps the confusion of identity in pastoral care and counselling has as much to do with hesitancy around making theological claims as it has to do with criticism

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[20] Webster (1998, pp. 6-8) draws the distinction between *Bildung* (formation) and *Wissenschaft* (putative scientific methodology) in the nature of enquiry. In the former there is a recognized *canon* of texts; education includes learning the texts; argument involves citation. In the latter the emphasis is on enquiry rather than citation, with a decline in use of texts related to an antiauthoritarian stance. It seems that the question of "authority" is important to consider in the place and role of theology in pastoral care and counselling. Generally speaking, in secular liberal individualism, arguably the prevailing cultural ideology in the One Third World, there seems to be some resistance to the concept of authority. Perhaps this has its roots in the Enlightenment project, where the nature of enquiry encouraged the challenging of dogma. Perhaps it is endemic to the human condition (see the Creation myth in Genesis). While some resistance is probably necessary and adaptive, a universal resistance to authority may reflect an existential and cultural malaise. The prevailing cultural ideology does nothing to challenge this malaise. I question simply whether a cultural resistance to authority per se has contributed to the decline of the role of orthodox Christian theology in the field of pastoral care and counselling.

[21] He writes,

> One consequence of this normalization is that it has made it increasingly difficult for practitioners within the various subdisciplines of theology to state with any clarity what is specifically *theological* about their enquiries. The theological disciplines have, in effect, been "de-regionalized," that is, they have been pressed to give an account of themselves in terms drawn largely from fields of enquiry other than theology, fields which, according to prevailing criteria of academic propriety, more nearly approximate to ideals of rational activity (1998, p. 14)

from some secular quarters.[22] Webster proposes *theological* theology as a response to the disorder he perceives in modern Christian theology. He proposes an understanding of theology as the articulation of "Christian difference" (1998, p. 20).[23]

Webster is not alone in this move. There have been similar moves made in other fields during the 1980s. One instance is George Lindbeck's (1984) work and his theory of intratextuality in the field of narrative hermeneutics. The social theorist John Milbank (1990) orders the relationship between social theory and theology in the same way. He argues for social theory arising out of the Church's theology, and not the other way around. Alisdair MacIntyre (1984, 1988) calls for a Tradition-constituted and a Tradition-constituting enquiry in the field of moral philosophy. Stanley Hauerwas (1989) takes a similar position in the field of Christian ethics. Each of these recognised authorities in their respective fields has proposed an *asymmetrical* relationship between the Christian narrative and related secular disciplines. In their respective fields they have sought to embed secular fields of thought within the Christian metanarrative.

What has afforded the context for these moves to take place? It is the demise of modernity and the advent of postmodernity. Modernity proposed a neutral place from which to view objectively phenomena under investigation. Postmodern critique has exploded the myth of the view from nowhere. It is now widely accepted that there is no stance that is not already theory-laden, no place of universal understanding, no value-neutral place from which one can dispassionately discern amongst competing claims. The demise of the project of a universal canon of rationality has enhanced the recognition of a plurality of perspectives and afforded greater freedom to "minority" voices. Christian theologians bring the wisdom of their own tradition, informed by other fields of knowledge couched in the grammar of faith, hope and love.

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[22] In chapter 10 "Discerning signs of the times" of his recent book *The sky is red*, Kenneth Leech (2003) discusses the sundering of pastoral care from the theology of pastoral care. His objection is not to secular practitioners offering pastoral care and counselling; it is to Christians purporting to offer a pastoral care and counselling divorced from its theological moorings.

[23] Webster (1998) borrows this term from John Milbank (1990, p. 381). See Milbank, J. (1990). *Theology and social theory: Beyond secular reason.* Oxford: Blackwell.

A *Theological* Pastoral Care and Counselling

I wonder whether pastoral care and counselling might rediscover some of its identity and distinctiveness through reclaiming some of its theological heritage – a *theological* pastoral care and counselling. It would be founded upon an *orthodox* understanding of Christian theology, in the sense that one could articulate the content, methods and goals of theology in pastoral care and counselling without needing to borrow from affiliated disciplines.[24] A theological pastoral care and counselling would promote an asymmetrical relationship between theology and other disciplines that inform pastoral care and counselling. That is to say, rather than making a Tillichean correlationalist move, or following the more recent critical correlation method of David Tracy, with related fields of thought (such as the social sciences),[25] a theological pastoral care and counselling would accord primacy to the Church's understanding of the ministry of pastoral care and counselling sourced in Scripture and the Spirit. That is not to say that insights from social sciences and other anthropological disciplines would be dismissed, or even set to one side. Rather there would be an asymmetrical relationship, within which the usefulness of insights generated from natural fields of inquiry would be annexed on an ad hoc basis to assist with explicating or interpreting the experience. One would have recourse to insights from the natural and social sciences where they might nuance further, or refine those theological categories germane to the "cure of souls," to the wholistic care of the human person. The caveat remains that such addenda would never supplant the primacy

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[24] I use the term *orthodoxy* as Webster (1998) has defined it.

> Orthodoxy is participation in a tradition which directs itself to a source of convertedness. It involves a setting of the self – including the knowing self – within patterns of common action and contemplation, of speech and hearing. When they function well, those patterns are sufficiently stable to provide focus, and yet sufficiently aware of their provisionality to enable self-critical adaptability and to offer a check against stasis (p. 23).

[25] Correlationist moves in theology can truncate the reading of Scripture. There is the risk that one refers to only those parts of Scripture that are amenable to, or resonate with, the secular discipline with which the correlation is being drawn. Hence the "dialogue partner" may set the parameters and the agenda for the discussion. An example would be the anthropological category of sin in Holy Scripture. Where this concept does not find a parallel in the social sciences, the risk is that not only is it omitted from the round table discussion in correlationist methodologies, it may be overlooked in the reading and interpretation of Scripture itself. The question arises as to what happens to the canon of Holy Scripture, and the understanding of its theological anthropological register with a shift in emphasis in social science categories for conceptualising the human person? It is for this reason I wish to explore alternatives to the correlationist moves in theology that appear to have dominated North American Protestant pastoral care and counselling theory at least since the work of Paul Tillich.

of the Church's own categories and registers for its understanding, interpretation and practice of the ministry of pastoral care and counselling [26] (see Figure 1).

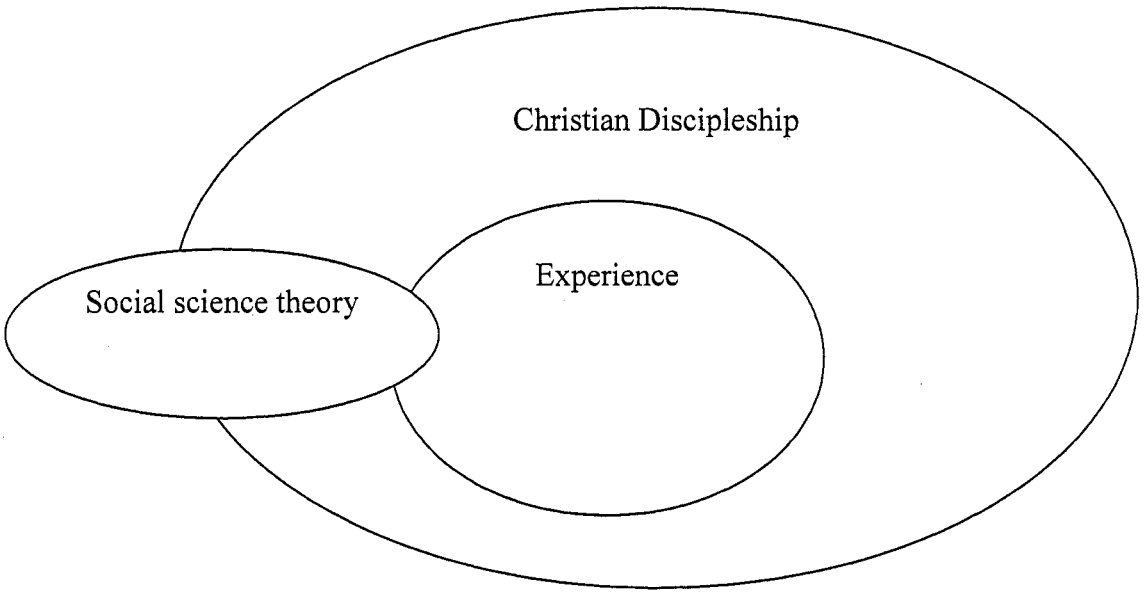

Figure 1. A diagrammatic representation of a theological pastoral care and counselling, depicting the location of experience within the embodied Christian faith, with recourse to relevant social science theory on an ad hoc basis. The term *Christian discipleship* connotes that the process of locating the experience of recipients of pastoral care and counselling is more than an hermeneutical exercise employing *Christian metanarrative*. The process invites the use of all the theological resources and ecclesial practices embodied in the Church.

This reorientation might assist with the recovery of the identity and the distinctiveness of pastoral care and counselling, which seems to have diminished through the field's

[26] It is probably helpful to clarify some of the questions that arise with correlationist methodologies. Where one seeks to make correlationalist moves in pastoral care with secular theories, the question which often remains unasked is, Why would one choose this particular theory and not another? What is so compelling about an intrapsychic understanding of personality as opposed to an interpersonal one? What does an individualist concept of relational dynamics have to offer over a systemic understanding? Is it simply a matter of personal preference? Perhaps a question to ask is, What does use of theory from a related discipline add to the theory and practice of pastoral care? Moreover prevailing theories in related secular disciplines may change. If one has allowed a popular theory to set the terms for the way in which pastoral care is understood and delivered, what happens when the theory becomes outmoded, or is no longer deemed sustainable? In this study, adherence to a particular theory from the social sciences, or the quest for an all-embracing explanatory schema, may have detracted from attentiveness to the particularity of parents' stories.

preoccupation with correlation to secular fields of knowledge. Pastoral care and counselling is sourced in the nature and activity of the Triune God. Specifically it finds its ultimate expression in the person of Jesus Christ, the one in whom God self-discloses fully. Pastoral care and counselling is effected by grace, in and through the power of the Holy Spirit. As such the vision of pastoral care and counselling and the logic underwriting and inspiring such vision are peculiar to the discipline. To reduce the field to the lowest common denominators it shares with related secular fields in an effort to facilitate dialogue according to the canons of putative universal reason guts the field of its distinctiveness. This agenda by reason of the particular subject nature of the field is doomed to failure from the outset. The noetic principle of pastoral care and counselling is the Word of God. That is not to say, a doctrine of Scripture or revelation determines the field. What governs the field precedes both. In Webster's (1998) terms the "object" of the field is "inalienably *subject*."[27] In any theological endeavour (including the theology that underwrites pastoral care and counselling) the object and the subject of theology is God. The notion of the Word of God in this sense is epistemology. It demonstrates how the knowledge of God is possible and real. There is a sense in which the epistemology of pastoral care and counselling will at some level remain fundamentally incongruent with the epistemologies of related secular disciplines.

It might be argued that such a stance is *fundamentalist*. Historically the theory and practice of pastoral care and counselling has probably needed to reconcile itself with the rapid expansion of knowledge in the social sciences. It is probably timely to enquire whether facets that were and are intrinsically valuable to the field of pastoral care and counselling have been left behind in the process. The question simply is, "What would pastoral care and counselling look like if it were to retrieve intentionally aspects of its ecclesial heritage?" In this sense the proposed move could be one which sees the field recovering dimensions of its original identity rather than making exclusive truth claims for itself.

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[27] He writes, "The object of theology is nothing less than the eschatological self-presence of God in Jesus Christ through the power of the Holy Spirit" (1998, p. 19).

I have set out some of the foundations for the relationship between theology and the social sciences in an ecclesially located and theologically grounded pastoral care and counselling. I now consider the relationship between theology and experience.

Relationship Between Theology and Experience

The relationship between theology and experience is ambiguous and varied in the theory and practice of pastoral care and counselling. While theology needs to connect with one's personal experience, and that theology and experience in this sense belong together in Frances Young's terms, there are consequences to allowing personal experience to set the parameters for theology. There is a perennial risk in beginning theology with anthropology that a discussion of divine nature and activity transmutes into a discussion of human nature and activity. The relationship between divine activity and human response is always asymmetrical. God's activity is always "gratuitously gracious" in Karl Barth's terms. One does not need to exact God's grace. Augustine, following St. Paul emphasises that God gives grace freely. God's grace is that which prepares the ground for human response to God's grace. God's activity is always prior to human response.

I propose a relationship between theology and experience that reflects this reality – an asymmetrical relationship. This represents a variation on the understanding of the role of experience in contemporary North American Protestant (and Roman Catholic) pastoral care and counselling theory and the theology that underwrites it. Rather than according priority to experience and even permitting experience to recast the form and the content of theology,[28] I am suggesting that theology has the capacity to interpret the human condition and to locate that condition within the account of God's creative and salvific acts in the people of Israel, and definitively and conclusively in the person of Jesus Christ. Setting this priority prevents experience from determining the content of theology, and avoids two pitfalls. First, sourcing theology in one's own experience can reduce

[28] For example, I wonder whether Kinast (1990) in his definition of pastoral theology may overstate the situation when he argues that pastoral experience takes precedence over theology. He maintains that pastoral experience determines the relevance of theology in the specific context, and that pastoral experience may reformulate theology, shaping its content and methods (p. 873).

theology to anthropology. Second, human experience as often as not is self-deceived and self-deceiving. Where one accords priority to experience in an exercise of theological reflection, one limits the ability of theology to critique fully the experience and the human condition. Theological methodology needs to permit the theological reflection to draw on other categories than merely those present in the experience.

In according priority to theology, it is probably helpful to identify what theology has to offer to the practice of pastoral care and counselling. Theology provides concepts that resonate with those from psychology and social sciences in analysing pastoral situations, as well as the ecclesial resources of Scripture, the sacraments and prayer. It discerns God's being and activity in the situation. Theology through a narrative hermeneutic assists with discovering and sharing meaning in a pastoral situation. Word and sacrament exist as primary forms of sharing and celebrating the faith. Theology analyses, interprets and critiques the pastoral situation, locating it in the broader context of the Church's life. It prevents the situation from being isolated or asserting a self-destructive independence. At the same time, theology itself needs to remain self-critical, guarding against dogmatism (Kinast, 1990, pp. 873-874).

What does the asymmetry of the relationship between theology and experience mean in the context of this study, focussed as it is on member parents' reflections in a Faith and Light community? In looking at the pastoral care of parents of offspring with an intellectual disability, the fundamental question (which is essentially soteriological) becomes, "What does Jesus Christ have to offer these parents?" What *pastoral* resources does the pastoral carer offer them? On this understanding the question is not, "*Based on the reported experience of these parents,* what pastoral package does the carer hold out?" Were the question cast in this manner, it might restrict Jesus Christ and the ministry of care that he embodies to that which lies within parents' lived experience. One risks allowing the needs of parents to set the parameters for how one defines Jesus Christ, and thereby wresting Christology and its soteriological impact merely to meet pastoral need. Jesus Christ may become a tailor-made response to a particular problem set. The corollary is that if Jesus Christ does not meet one's need, one is then led to the

assumption that Jesus Christ is not who he claims to be, and is of limited good. This appears to be one of the significant risks in this specific situation of allowing parents' reported experience to set the terms for theology. Therefore, the experience of parents will shape or form how pastoral care and counselling is delivered, rather than determining the nature of pastoral care and counselling itself. In this sense the experience of parents will afford carers the potential to offer a more nuanced and sensitive attentiveness. Providers of pastoral care and counselling will have recourse on an ad hoc basis to techniques of care which may have developed in auxiliary and related disciplines. The experience of parents may set the matrix of care; it does not alter the nature of pastoral care and counselling itself.

This chapter outlines some preliminary contours of an ecclesially located and theologically grounded pastoral care and counselling. The relationships between theology and related secular disciplines, and between theology and experience would be asymmetrical. In the next section I sketch briefly other features of the proposed approach.

Narrative Hermeneutic

Theological pastoral care and counselling would not be inconsistent with the "cultural-linguistic" taxonomy proposed in Lindbeck's (1984) theological typology.[29] In Lindbeck's terms the cultural-linguistic category understands religions as "comprehensive interpretive schemes, usually embodied in myths or narratives and heavily ritualised, which structure human experience and understanding of self and world" (p. 32). Elaborating upon the human tendency to structure life in stories and the power of interpretations to shape life and express care, Charles Gerkin draws on Lindbeck's typology. Gerkin (1997) underscores the role that the faith community plays

[29] Lindbeck (1984) has proposed a three-fold typology of approaches to theological work: propositionalist, experiential-expressivist, and cultural-linguistic. A propositionalist taxonomy posits that theological propositions correspond directly to what is real and true. An experiential-expressivist taxonomy is premised upon the existence of a common core of human religious experience that may have diverse forms of expression in different cultures. His work has been criticised on the grounds that it is unlikely any theological approach will fall neatly into one of the categories. The typology is itself a metaphor and as such will be an interpretative aid rather than a definitive classificatory schema.

in caring for others by providing an hermeneutical context within which people can locate their own experiences and make sense of them. He observes,

> [Pastoral care within the psychotherapeutic model] fails to recognise that one of the most basic caring functions that a community of faith can offer is a storied context of ultimate meaning within which life can be lived. Expressed another way, one of the fundamental structures of care that life in a community of faith can and should offer is a story or grammar – a way of speaking about people's circumstances – that can connect people's life experience with the ultimate context of meaning contained in the Christian gospel (1997, p. 103).

Belonging to a faith community is to adopt a *grammar,* an interpretive schema that structures one's understanding of self and the world. "It has the unique ability to provide people with a storied context of ultimate meaning for their lives... a meaning-filled nesting place and thus provide the most elementary context of care" (1997, p. 110).

Gerkin locates pastoral care and counselling in the dialogical space between the story of the Christian community and the individual stories of its members.

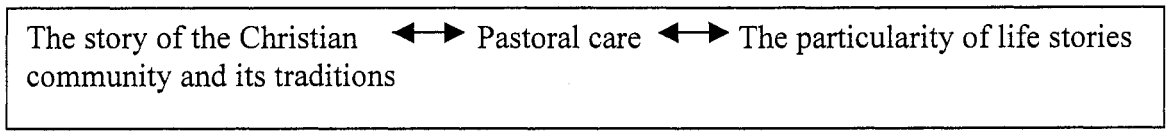

Figure 2. A diagrammatic representation of the location of pastoral care in the dialogical space between the Christian communal story and life stories of people related to the community (Gerkin, 1997, p. 111).

Gerkin's model of pastoral care and counselling facilitates "serious, open dialogue" in the process of searching for authentic connections between the Christian story and life stories (p. 112). The provider of pastoral care and counselling dances along the continuum from a propositionalist stance in Lindbeck's typology ("proclamation" of the Christian story), to an experiential-expressivist stance (articulation of individual and shared experience). She or he has responsibility for nurturing growth of the Christian story and its relation to Christian tradition, and the growth of individual stories.

Gerkin's use of a narrative hermeneutic and his understanding of the function of pastoral care and counselling within this hermeneutic are helpful. A theological pastoral care and

counselling would endorse his model, and simply emphasise the asymmetry of the relationship between the Christian story and individual (and shared) stories. George Lindbeck (1984) has coined the term "intratextuality" to describe the way in which the Scriptural narrative world absorbs other narrative worlds. The story of Jesus is that into which one's own story is taken up. It is an asymmetrical relationship (*intra*-textuality) between stories rather than a correlational one (*inter*-textuality). It is not a case of translating the Scriptural world into other worlds. The Scriptural text absorbs the world, rather than the world absorbing the text. This is not intended as a totalitarian claim. It is not a case of forcing every story to conform to the Christian story. The Christian metanarrative is the hermeneutical framework within which all other stories are located. Human stories find their place within the narrative of God who rescues a broken world.

By understanding one's own story in the context of the story of Jesus, new possibilities appear for the way in which one interprets and lives one's own story. Locating one's own story within the story of Jesus opens up options for renewal and transformation. By God's grace parents may understand their own stories in more liberating and hope-filled ways as they locate their stories, and their stories are located for them within the Christian metanarrative. The relationship between the Christian narrative and one's own narrative is and remains fundamentally asymmetrical. It recognises and safeguards the distinctiveness of Jesus, the person in whom the perfect union of two radically incommensurable natures takes place, and whose own story must always remain incommensurable at some level with any human story. At the same time Jesus' salvific deed establishes and opens up the space in which one's own story can be transformed by God's grace.

What would this mean in practice? What does it mean to see one's story absorbed into the canonical text? An example is that given in Jinkins (2001) where he cites Basil the Great's use of Scripture to bear directly on the pastoral situation of a fallen virgin. Her narrative woven into the Christian story is brought into touch with the healing and redemptive power of a profoundly caring God, who seeks out human beings in order to

"save" them. [30] One's story finds its place within the narrative of the life, death and resurrection of Jesus Christ and the life of God's Spirit. This is an example of what I understand by a *theological* pastoral care and counselling.

Other Theological Concepts

Sauter (2003) [31] highlights the need for the theology that underwrites pastoral care to critique the deluge of anthropological insights generated by the secular fields of knowledge. A theological pastoral care and counselling will afford priority to primary theological motifs of Scripture and allow these to inform the field's interpretation of the contemporary context.

> In probing this situation, theology will meet with that which drives our contemporaries, that which threatens them, and that which they need. But we can

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[30] Jinkins (2001, pp. 124-125) provides an example of pastoral care in the ancient catholic church through a letter of Basil the Great (c. 330-379 CE) to "a fallen virgin." The point that Jinkins underscores is that Basil in responding to the woman in need has recourse to the character of God (as a searching shepherd) as revealed in the life of Jesus Christ. It is the writings of the New Testament that provide the basis for the understanding of who Jesus Christ is. Basil the Great, "Letter XLVI," In *St. Basil: Letters and select works,* Nicene and Post-Nicene Fathers, second series, P. Schaff and H. Wace (Eds) (1983), Blomfield Jackson (trans.) Grand Rapids, MI: Eerdmans at 8:152.

> The Lord wishes to cleanse you from the trouble of your sickness and to show you light after darkness. The good Shepherd, Who left them that had not wandered away, is seeking after you. If you give yourself to Him He will not hold back. He, in His love, will not disdain even to carry you on His own shoulders, rejoicing that He has found His sheep that was lost. The Father stands and awaits your return from your wandering. Only come back, and while you are yet afar off, He will run and fall upon your neck, and, now that you are cleansed by repentance, will enwrap you in embraces of love. He will clothe with the chief robe the soul that has put off the old man with all his works; He will put a ring on hands that have washed off the blood of death, and will put shoes on the feet that have turned from the evil way to the path of the Gospel of peace... If any of those who think they stand find fault because of your quick reception [back into the fellowship of the Church], the good Father will Himself make answer for you in the words, "It was meet that we should make merry and be glad for this" my daughter "was dead and is alive again, was lost and is found."

Note that the language employed by Basil the Great is entirely sourced and centred in the person of Jesus Christ. The situation of the "fallen virgin" is absorbed into the Gospel narrative of which Jesus Christ is the subject.

[31] Gerhard Sauter, Professor of Systematic and Ecumenical Theology and Director of the Ecumenical Institute in the Faculty of Protestant Theology at the University of Bonn in Germany, is an example of a recognised contemporary Lutheran theologian who brings theological categories to bear on the conceptualisation and delivery of pastoral care to the people of God. In *Gateway to Dogmatics: Reasoning theologically for the life of the Church* Sauter (2003) addresses the relationship between dogmatics and pastoral care in the second part of his book under the heading "Dogmatics in the Church." He advances a number of theses, grounded in a view that theology (and more particularly dogmatics) not only has the capacity to interpret the human condition, but to locate it within the ambit of God's creative and redemptive activity supremely manifest in the person of Jesus Christ.

> recognize the modern situation only if we do not abandon ourselves to these drives but know their limits, namely, the context that enables us to see the inalienable and permanent human questions in the flood of information, and helpfully, therefore, to shed light on the nature of humanity (2003, p. 138).

Citing the approach to pastoral care of the 19th century theologian and pastor, Johann Christoph Blumhardt (1805-1880), Sauter argues that theology is not something that needs to be translated when being applied to different pastoral situations. Rather it is "the grammar of faith and hope and love" (2003, p. 148). Within this grammatical lexicon, several primary theological concepts will find a place in a theological pastoral care and counselling: grace, the Reign of God and broken self-knowledge.

Grace

First, grace is fundamental to the theory and practice of pastoral care, a care which facilitates the alignment of a person's will with God's will. Pastoral care and counselling is grounded in grace, in the divine activity of creation and recreation (which is salvation). It helps recipients of care to see themselves within the purview of God's grace. In Thesis 34, Sauter summarises, "The inner grounding of pastoral care is the grace of God that orients our human wills to God" (2003, p. 141). He relies on an Augustinian understanding that sees grace not as a means of perfecting humankind's actions (in Pelagian terms), but as that which reorients a will resistant to the good God has purposed for, and gifted to, humankind. It is prayer that sets humankind's actions within the context of God's being and activity.

> When grace comes to us, as it does in prayer, we receive freedom, and our wills are wholly and utterly oriented to God. Grace does not supply what we lack. Instead, it puts us in a position where we can know and will the good (2003, p. 141).

For pastoral care and counselling to be *pastoral*, it needs to be an instrument of grace. That is of the essence of *pastoral* care and counselling. It is administered in and through the grace of God. Pastoral care and counselling interventions will only be useful insofar as grace has disposed the carer to proffer care to the other person, and that same grace has

disposed the recipient to receive it. It is by the grace of God that one cares for a fellow being in the first place.

Reign of God

Second, pastoral care and counselling is an invocation of God to set up the reign of God in a person's life.[32] It introduces the redemptive power of God therein. In listening to a client, pastoral carers will ask themselves questions such as: Where is the place that the Reign of God needs to be set up in this person's life? What is involved in the Reign of God establishing itself in this person? Healing? Restoration? Transformation of will?

Broken Self-knowledge

Third, the establishment of the Reign of God in a person's life in pastoral care and counselling involves hard struggle, because one of its requirements is a revision of self-identity. Humanity wrestles with the problem of self-deception. Left to its own devices, humankind is not capable of giving an adequate theological description of itself. Invariably human beings seek to cast themselves in a better light. Luther has contended that if human beings saw themselves as they actually are, they would be destroyed by the self-revelation. His hope was that in and through Jesus Christ, humanity learns to see itself as God sees humanity in Jesus Christ.[33] To this end pastoral carers will address themselves to the theological concept of broken self-knowledge in their own lives and in the lives of those receiving care. Part of the care offered may entail assisting others to rediscover their identity as forgiven and redeemed children of God.

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[32] Karl Barth based his view of Christian ethics on the Lord's prayer: "Thy Kingdom come, Thy will be done..." It is an invocation for the establishment of God's reign in one's life. Sauter (2003, p. 146) echoes this idea in Thesis 36: "Pastoral care participates in God's setting up of his kingdom and in Christ's victory over the powers of destruction."

[33] Thesis 35 of Sauter reads: "Pastoral care can help us expose ourselves to the judgment of God and to accept this judgment." The corollary is that "Humanity is not defined by its constitution or its possibilities. It is defined by an event, the event of justification by faith..." (2003, p. 144)

Summary

This study explores the role of Faith and Light as a provider of pastoral care and counselling to families with offspring with an intellectual disability, with particular reference to the perspective of parents. I have begun by advancing an approach to pastoral care and counselling, which I have termed *theological* pastoral care and counselling. Theological pastoral care and counselling is sourced in the life, ministry, death and resurrection of Jesus Christ and all that those dimensions say about the divine reality. As life in Christ is Church life, theological pastoral care and counselling reasserts the ecclesial context within which Scripture, doctrine and tradition function, and from which pastoral care and counselling is interpreted and delivered. That ecclesial reality is fundamentally Trinitarian. Theological pastoral care and counselling proposes an asymmetrical relationship between the Christian metanarrative and related fields of knowledge. One of my concerns is that the prevailing recourse to social scientific methodology within the field is simply an attempt to create a taxonomy that is recognised in relativist secular culture. It is clear in the proposed approach that insights from secular disciplines are not ruled out. They may be precisely what are needed in offering meaningful and nuanced pastoral care and counselling. The difference is that these learnings would be annexed on an ad hoc basis to the Church's understanding and practice of pastoral care, rather than providing the explanatory schema within which pastoral care is interpreted and delivered. Theological pastoral care and counselling would cast the relationship between theology and experience as asymmetrical, in order to avail itself of the full gamut of theological resources at the Church's disposal.

The proposed approach would not find itself at odds with Lindbeck's "cultural-linguistic" taxonomy. Endorsing the role of the faith community in providing a meaning-making interpretive schema within which people can locate their experiences, it would also promote in Lindbeck's terms the notion of "intratextuality" where the Scriptural narrative world is placed to absorb other narrative worlds. Theological concepts such as grace, Reign of God and broken self-knowledge will combine to function as a compass by

which theological pastoral care and counselling orients itself. They will also contribute to the grammar of the field.

One of the goals of this paper is to explore how this proposed understanding of pastoral care and counselling measures and is measured by what happens in Faith and Light. In the next chapter I turn to the community of Faith and Light, tracing its history and development, some features of its spiritual practices, and some of its theological motifs.

Chapter Three

COMMUNITY CONTEXT – FAITH AND LIGHT

Introduction

On the website of Foi et Lumiere (http://www.foietlumiere.org) appears a quotation from Pope Jean Paul II. "One of the callings of Faith and Light is to let people with an intellectual disability feel that they are never useless nor alone." Faith and Light is an international federation of nearly 1500 communities scattered across 75 countries. People with an intellectual disability, together with their families and friends, form the heart of each Faith and Light community. Typically the communities are comprised of 20 to 30 members, who meet together in "faith, fiesta and friendship" once a month. The small size of the communities permits members to be present to one another, a hallmark of the movement's spirituality. Cahoon (1983) describes Faith and Light as "an attitude to the handicapped, and a belief that every human person has a God-given right to be treated as such" (p. 62). Its role is to mediate the gifts of people with an intellectual disability, who call others to simplicity of relationship in their daily lives. In this section I give a descriptive account of the Faith and Light community, based largely on literature published by the International Organisation of Faith and Light.

Faith and Light is a *community movement*, not a residential movement. As well as encouraging people with an intellectual disability to recognize and to use their gifts, and it invites all members to discover the joy of friendship. Faith and Light promotes the formation of trusting friendships through sharing, prayer and celebration. It promotes a shift in perspective for parents, for siblings and for friends. It supports parents, encourages them to recognize the beauty and the giftedness of their children, and it invites parents to support other parents. It encourages siblings to recognize their sibling with an intellectual disability as a source of life and unity, capable of transforming their own lives. It encourages friends to recognize the invitation of people with disability to an

orientation of attentiveness, of tenderness and of fidelity. There is particular openness in Faith and Light to young people.

The Beginnings and Subsequent Growth

The seeds of Faith and Light lay in the pain of rejection Camille and Gerard Proffitt experienced in 1968[34] when they took Loic and Thaddee, their young sons with multiple disabilities, to Lourdes in France after having been excluded from a Diocesan pilgrimage. Marie-Hélène Mathieu, after learning of the experiences of the Proffitt family, met with Jean Vanier. Vanier had experienced pilgrimages with men with an intellectual disability with whom he lived in the L'Arche communities that he had co-founded, as times of renewal and grace. Mathieu and Vanier formed the idea of organizing a pilgrimage to Lourdes for people with an intellectual disability, their families and their friends. The pilgrimage was three years in the planning, and drew a mixed response.[35] The organisers formulated a charter to clarify the vision for the pilgrimage.[36]

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[34] They were exposed to ostracism and ridicule in Lourdes. The hotel management had their meals brought to their rooms to avoid embarrassment in the dining room; other pilgrimees crossed the road to avoid the sight of their sons; people at the Grotto commented that the children should have been left at home.

[35] They found support when they discussed their plan with other parents and friends in France, Belgium and England were encouraging. The Bishop of Beauvais, Mgr Desmazèires lent his support and attended the first meeting in Paris on 8 December 1968. Monseignor Rhodain, the founder of "Caritas France" was also a supporter. Other Roman Catholic clergy in France believed that the movement placed too much emphasis upon suffering, and that it was not in keeping with the vision of the Second Vatican Council. In the video of the 2001 pilgrimage, Mathieu recalls that there were "all kinds of difficulties... People thought we were crazy."

[36] The charter sets out the founding ideas behind Faith and Light and reads as follows:

> The pilgrimage will not be a gathering of individuals, but a coming together of small communities of "human size," at the heart of which the mentally handicapped people will find themselves perfectly integrated into the group. We shall join the pilgrimage and stay in lodgings as communities.
>
> It will be during fraternal gatherings of mutual exchange and in prayer that the preparation will be done.
>
> This pilgrimage must help the parents to take on this trial and to discover the whole person of their child, to see him/her through his/her handicap as a child of God, capable of a true spiritual life and, in fact, not handicapped at all in his/her relation with God.
>
> This pilgrimage must not bring false consolation to the parents, by raising illusory hopes of healing. It must be an opportunity, not for creating false hopes or giving imaginary rewards, but for bringing true hope to the handicapped people and their friends and families. It must also be an occasion for giving them profound support as they face their trials and sufferings.
>
> The pilgrimage must signify the incorporation of the handicapped people into the Church. Being equal in Jesus as brothers and sisters, they must be welcomed, without reservation into our communities: parishes, groups, and movements, etc.

The leaders of the pilgrimage emphasized that they sought a transformation in outlook ("healing of hearts") in those without an intellectual disability, rather than any miraculous healing of those with an intellectual disability.[37] Those who chose to become part of the pilgrimage arranged themselves in groups of 20 to 30 during the preparation. These small groups gathered as 12 000 pilgrims, of whom 4 000 had an intellectual disability, from 15 different countries on Good Friday, April 9, 1971 at the Massiabelle grotto in Lourdes. Their shared experience of joy and communion at Lourdes was profound. On Easter Monday, in response to the call to continue to work for the inclusion of people with disability in the Church and society, Jean Vanier suggested to the 350 leaders of the pilgrim communities, "Continue to meet together in small communities, do everything that the Holy Spirit inspires you to do." This invitation marked the birth of Faith and Light.

In 1975, Pope Paul VI welcomed Faith and Light to the Basilica of St. Peter in Rome, where 12 000 pilgrims attended a mass and presented Cardinal Poletti with lists of the names of members of their Faith and Light communities.[38] Marie-Hélène Mathieu regards this event as the consecration of Faith and Light by the universal Church. Small communities flourished as the pilgrims returned home and shared their friendship with others. In 1981, Faith and Light communities from 23 countries met again at Lourdes. It was described as a pilgrimage of gratitude for the revelation of the beauty and giftedness in people with an intellectual disability, during which many people renewed their

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[37] In an unpublished paper delivered at the Faith and Light International Conference in Warsaw in 1994, Marie-Hélène Mathieu recalled of the first pilgrimage, "This miracle of the healing of hearts, we saw visibly. It really came through with so much force. Parents were accepting their handicapped child just as he was for the first time. A child was smiling for the first time..." She reiterates in a video documenting the 2001 pilgrimage that parents going to Lourdes hoping for the miracle of intelligence for their children would be "very frustrated."

> We were going to Lourdes to ask for one miracle... the miracle of our hearts... that we might recognize that each person with disability is important and unique... that in order to be happy they are asking for one thing – to feel useful, loved and to discover that they are precious.

[38] Pope Paul VI affirmed the vocation of Faith and Light in the following words:

> You have a special place in the Church where your simple faith, your prayer, the appeal for affection in your eyes, your generous heart, all remind Christians of the only ways which lead to God. You have a place in society, where thank God, you have many friends who love you and support you and remember that they too depend on you (Cahoon 1983, p. 64).

commitment to people with an intellectual disability.[39] Thirteen thousand pilgrimees from 60 countries gathered in 1991 at Lourdes and proclaimed the ecumenical vocation of Faith and Light around the person with disability, with the cry, "Father, unite us all so that the world may believe." In 2001, over 16 000 people from 73 countries met at Lourdes to celebrate Easter around the theme of "Come to the waters." The gifts of joy and communion were again evident.[40]

Foundational Documents

As the movement grew, community life expressed itself in a variety of ways throughout the world. The need for a charter to define the vocation, inspiration and activities of Faith and Light, and for a constitution to set out its aims, its organization and structure became apparent. The Charter and Constitution were formally approved in 1982.[41] Both documents serve to hold the movement to its instigating vision.

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[39] Pope John Paul II in his address to the pilgrims commented on the importance of the "family circle" or "an institution or small community run as closely as possible on family lines" to people with a disability. He described Faith and Light as,

> a place where personal relationships and the warmth of human contact enables the handicapped person to fulfill his or her deep need for friendship and security in developing human, moral and spiritual qualities as far as is possible (Cahoon, 1983, p. 65).

[40] Pope John Paul II in his letter to the pilgrims emphasized people with an intellectual disability as being "the very heart of the great family of Faith and Light." He affirmed the vocation of Faith and Light of announcing "the eminent dignity of every human person," and referred to the hope and confidence that families and individuals have found in the movement. He promoted intellectual disability as a call to rise above self-centred living and to commit to solidarity with one another. He re-iterated his belief that those with an intellectual disability call into question "understandings of life linked only to personal satisfaction, appearances, efficiency." He concurred with the prophetic vocation of Faith and Light to affirm life and to advocate for the preferential treatment due to those most in need in society. He validated the ecumenical vocation of Faith and Light, based on the Christian belief that every person is "a gift from God, with inalienable dignity and rights."

[41] Member countries began working together on a Charter and Constitution in 1978. The General Assembly, held in Lourdes on October 26, 1980, adopted a provisional Charter and Constitution for one year, during which time national co-ordinators were able to suggest amendments. The General Assembly at Wetherby, England in 1982 voted unanimously to adopt the Charter and Constitution. Subsequent General Assemblies in Rome (1984), Santo Domingo (1986), Edinburgh (1990), Warsaw (1994) Quebec (1998) and Rome (2002) ratified further amendments. A majority of 75% is required to adopt or to amend the Charter and Constitution.

The Charter

The Charter defines the spirit of Faith and Light and it is to be read with the Constitution (Prologue to the Constitution). The prologue to the Charter reads: "Faith and Light was born of a desire to help people with an intellectual disability and their families find a place within the Church and society." It involves a vocation of *presence* to one another through gathering together to share suffering and to celebrate giftedness (I, 1). Joy characterizes community life issuing from fidelity to friendships, and a vocation of celebration is central to gatherings. Members remain attentive to those on the periphery of community life (I, 2). Presence to one another and celebration are joined in the vocation of praying as a community (I, 3). The vocation of fidelity to friendships finds expression in shared time between meetings, termed "fourth time" (I, 4). Integration of communities and their members with local faith communities, organisations and agencies allows for the expression of Faith and Light's ecumenical vocation. This vocation issues out of the gift of people with an intellectual disability, who through their simplicity of heart and humility, become a source of unity in and between families, faith communities, and other groups (I, 5).

The inspiration of Faith and Light arises out of the Christian belief that each person is loved by God and that Jesus Christ is revealed in the person with an intellectual disability (II, 1). It affirms the value and the dignity of every person, created in the image of God (Gen. 1. 26,27).[42] Faith and Light acknowledges the need for community (II, 2),[43] and calls its members to develop competence in working with people with disability (II, 3).

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[42] Therefore, every person has "the right to be loved, recognized and respected for himself or herself and in the choices he/she makes; the right also to receive whatever help is necessary in order to progress at every level spiritual and human" (II, 1). Being loved finds concrete expression in being recognised, being respected and being enabled to grow in all dimensions of one's being.

[43] It recognizes that growth in faith and love comes through a warm and supportive environment sustained by real friendship. There is a mutual sharing of gifts that each member brings. Real and liberating relationship with people with disability comes about through the transforming work of the spirit of Jesus Christ in people's hearts so that people recognize his presence in others. Communities are places of peace and joy, and mediate or reveal the giftedness of people with disability. These gifts include their capacity for welcome, their simplicity and their tenderness.

Section III of the Charter defines the activities of Faith and Light. It is a community movement, where relationships between members find their source and their fulfillment in Jesus Christ (III, 1). Faith and Light is not involved in establishing or managing residential, therapeutic or educational facilities (III, 2). Faith and Light communities seek to co-operate with other organisations supporting people with an intellectual disability and their families (III, 3). The communities throughout the world are in solidarity with one another as members of a single family, seeking to live in love and unity (III, 4).

The Constitution

The Constitution sets out the objectives of the movement, and defines what a Faith and Light community is and how it organizes itself at different levels.

Section I of the Constitution sets forth the objectives of Faith and Light communities. The communities aim to foster strong connections between people with disability, their families and their friends (I, 1). The movement promotes family ties between communities through regional, national and international meetings and through pilgrimages (I, 2). It provides appropriate formation for members at all levels (I, 3), and organizes financial solidarity amongst its members (I, 4). Faith and Light encourages respect for cultural and religious differences and the integration of communities within the surrounding society and the Christian community (I, 5). It collaborates with other associations serving people with an intellectual disability (I, 6). Faith and Light incarnates a stance of unconditional love towards people with an intellectual disability, holding them as children of God capable of growing in spiritual maturity (I, 5).

Faith and Light communities consist of people with a disability surrounded by their families and friends, and communities meet at least monthly. There is a minimum of 10 members, and a maximum of 50 members. When communities reach more than 50 members they divide. Communites agree to abide by the Charter and the Constitution (II, 1). A probationary period exists for any group seeking Faith and Light membership (II, 2). A leader and a co-ordinating team co-ordinate the life and the activities of a

community. The co-ordinating team contains four to eight members, comprising one parent, one friend, a chaplain and where possible a person with an intellectual disability (II, 3). Provisions cover the recognition of a probationary community (II, 4), and the leaving or dismissal of a member community (II, 5).

Section III of the Constitution sets out provisions for regional and national organization, covering the organization of regions (III, 3-6) and countries (III, 7-13), probationary membership (III, 14), recognition of a country (III, 15), creation of "provinces" (III, 16), and dismissal of member countries (III, 17). Section IV prescribes the international organization of zones (IV, 4-9), and continents (IV, 10-14). Section V defines the membership, the role and the powers of the International Council. Section VI sets out the terms for the Management Committee, which attends to the management of the International Association of Faith and Light between meetings (VI, 3).[44] Finally Section VII outlines the provisions for International Meeting and the General Assembly which take place at least every 4 years.

The *Four Times*

The three aspects or times to any Faith and Light community meeting are sharing, prayer and celebration or fiesta. Sharing includes sharing in the word of God, and sharing in friendship with one another. Prayer includes liturgy. Celebration or fiesta includes sharing food together. It is left to the co-ordinating team to design the format that blends these three aspects in the most meaningful and appropriate way to each group. Typically groups allow three hours for each meeting.

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[44] The evolutionary nature of the movement was evident at the International Meeting and General Assembly that took place in Rome in September 2002. The voting members elected to revamp Faith and Light's global organisational structure, creating six "continents," led by newly-elected "continental coordinators." The membership of the International Council now comprises the International Coordinator, one or more Vice-International Coordinators, the Continental Coordinators, the International Chaplain and the cofounders (V, 1). Vanier indicated at the meeting that it was a move towards decentralisation. The aim of the restructuring was to reduce the membership of the International Council, to promote the growth of local communities, to enhance supportive links amongst member communities, and to make the international family more inclusive. It sought to foster a greater sense of belonging at local, national and international levels (from an unpublished address on *Structures* delivered by Roy Moussali at the International General Meeting in Rome on September 23 2002).

Sharing

Faith and Light emphasizes welcome and togetherness in its gatherings. Faith and Light began with people gathering together, spending time with one another and getting to know each other.

> The essential thing is to form personal relationships within which we discover the suffering and the gifts of one another, where we learn to know someone else by name… Through friendship, made up of tenderness and fidelity, we become signs of the love of God for one another (Charter I, 1).

In sharing time, members open up to each other to foster deeper friendship, trust and mutual support between members. Sharing in the gatherings typically occurs around a theme which the Guidelines suggest for each meeting. The community leader, one of the co-ordinating team members or the chaplain expands upon the Bible reading suggested for the month. The co-ordinating team in planning this aspect uses a variety of means to engage people through what they see, what they hear and what they experience. Often members will dress up in simple costumes and mime the readings. Mime provides an accessible means for people with disability to encounter the Gospel stories. It is helpful to include all community members in the re-enactment, which may be accompanied by music. By re-enacting stories from Scripture, the group seeks to experience the life of Jesus Christ in new ways, and grow in their knowledge of the heart. The other component to the sharing time is the smaller sharing groups. Here, members of the community break into groups of five to eight people which include people with an intellectual disability, parents and friends, and they reflect on what they have received through the sharing of the word of God. Group members can be creative in how they communicate what they have received, and may choose to gesture, to draw or to construct a symbol.

Prayer

The time of prayer seeks to nourish the spirit of members, to enable people to give expression to their inner life, and to allow all members to be able to participate irrespective of their religious affiliation. It often involves music and a simple liturgy,

where members bring to the larger group what they have reflected upon in their small groups. Some communities may use a chapel if it is available; other groups may gather around a table on which there are important symbols. The community praises and thanks God, and asks God for help. It is a time to commit the community and each member to God's care. It is important that each member irrespective of ability is able to contribute and participate. The *Guidelines for the First Year* encourage attention to planning to facilitate simplicity and joy in communal worship.

> Jesus came to announce the Good News to the poor. They are loved by the Father. Jesus gave his life for the flock. He feeds them with his Body. That is why the personal meeting and the celebration find their culmination in prayer, in union with God and the celebration of the Eucharist and/or other religious celebrations (Charter I, 3).

Celebration

Celebration is fundamental to Faith and Light. In celebration time, Faith and Light seeks to create inclusive experiences that incorporate aspects of thanksgiving, forgiveness, covenant, sharing and vocation, and contribute to communal and personal growth. The meetings often conclude with the fiesta or celebration where members gather around a table to share food. The style of celebration varies widely depending on the culture. It is a time when the group celebrates birthdays and anniversaries. Vanier describes the fiesta as a celebration recalling God's continued presence and parental care for the community. There is joy in connecting with one another, and joy remains one of the hallmarks of the movement.

> From faithful friendship springs the joy characteristic of the Faith and Light community. It is God who calls us together and enables us to discover the covenant which unites us: we are no longer alone. Meetings are characterized by moments of joy when we sing, dance or share a meal (Charter I, 2).

"Fourth Time"

Faith and Light encourages "fourth time", which is the time members spend with each other between meetings. It is a time of *fidelity* to the relationships members have with one another, and can take many forms –seeing a movie, sharing a meal, going on an outing,

attending a church service, visiting another community. Communities often plan for a special event each year outside the monthly meetings – a weekend together, a pilgrimage, a retreat, a holiday camp, time with the religious community with which a community may be twinned. The Charter sets out the significance of fidelity to friendship in the vocation of Faith and Light.

> Friendship deepens through time and presence. Between the monthly gatherings the members of the community choose to spend time together in smaller groups or just meeting one-to-one. They share stories, fears, dreams, hope, prayer, fun, service with others, a meal and other activities which nurture friendship: it is "the time of faithfulness" (often called the "fourth time") (Charter I, 4).

The *Guidelines 2001-2002* describe the ideal group of friendship which the coordinating team arranges, taking into account the location of each community member. It numbers five to six people, and is composed of equal numbers of people with an intellectual disability, parents and friends. It includes a member of the coordinating team or a long-standing member of the community. The group usually plans to get together once between each meeting and to remain in contact by phone or mail over the course of the month. The *Guidelines* provide ideas to promote the life of small groups of friendship each month. The aim is that the life of Faith and Light can percolate through to the smallest members, and that in a reciprocal way these small groups can breathe more life into the wider community group.

Some Theological Motifs

Cahoon (1983) has described Faith and Light as an attitude towards people with an intellectual disability and their families. Part of its charism is the shift in perspective or worldview towards vulnerability[45] that it lives and invites others to live. There appear to be several concepts that are fundamental to the transformed vision of humanity that Faith and Light has received and discovered as an organization (see Appendix A for Biblical passages that Faith and Light has frequent recourse to). Jean Vanier's thought has shaped

[45] The question of terminology is an important one. I propose to use the generic term *vulnerable* where other literature, including the Christian Bible, may use terms such as *weak*, *poor*, *wounded*, *broken* or *handicapped*. While no term is value-neutral, I have chosen *vulnerable* as being the least pejorative.

Faith and Light, and therefore his writing, especially in the area of spirituality, assists with an understanding of the movement.[46]

Spirituality

Vanier (1991, p. 6) describes spirituality as "the movement towards maturity of love." The spirituality of Faith and Light promotes the journey in maturity of love from illusion to reality, from self-centredness to Christ-centredness, and from avoiding pain and poverty to welcoming it in oneself and in others. It is a spirituality which is grounded in the cut and thrust of daily life. Vanier is emphatic that it is not a dualistic spirituality, separating the temporal and the spiritual. On the contrary, it is an incarnational spirituality. "The spirituality of a disciple of Jesus is a spirituality of incarnation, the Word made flesh" (1991, p. 4). People grow in their awareness of their bodies as temples of the Holy Spirit and as "instruments of the love of God" (1991, p. 5). Communion with Jesus Christ whose Spirit opens hearts to growth in maturity of love provides the impetus for the movement. It is nourishment through the Word and the sacraments that facilitates communion.

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[46] It is important to distinguish between the communities of Faith and Light and L'Arche. L'Arche communities are residential in that people with an intellectual disability and assistants create a family home together. Community life in Faith and Light more closely resembles that of a support group meeting monthly. Both organizations have grown from the inspiration and the initiative of Jean Vanier working with others. Vanier describes them as different and complementary communities, sharing the vision of God's love for the weakest and the most rejected, and of the capacity of these people to open others' hearts to compassion and to God.

> The fundamental goal of these two forms of community is the same: to welcome people with disabilities and to reveal their vocation to others and to work towards their integration into society and in Christian communities (1999, p. 14).

Both communities have an ecumenical focus and share similar organizational structures. Their ways of celebrating are similar, and both face the challenges of finding sufficient funding and committed assistants/friends. Vanier describes Faith and Light as "a family movement, where parents play a vital role" (1999, p. 15). He describes the relationship between the two communities as "brothers and sisters or at least first cousins" (1999, p. 15). Vanier calls for understanding and unity between the two communities as conflict arising from misunderstandings or jealousies can arise. The relative strength of each community in comparison to the other can vary between countries. Vanier believes that shared retreats play a key role in fostering unity, and in promoting the spirituality of the two movements. The International Chaplain of Faith and Light, Fr. Joseph Larsen distinguishes between the communities: L'Arche bases itself on the love of family; Faith and Light bases itself on the love of friendship.

For Vanier, one of the touchstones of Faith and Light is the metaphor of eating at the same table with people with an intellectual disability (Lk. 14.12-14). He distils the essence of his discovery in Faith and Light: the ability of those with an intellectual disability to disturb and heal others; a transformed understanding of suffering; and the way of littleness.

> Faith and Light is essentially a place of community, the bonding of hearts... Faith and Light is not just a place of fun or integration into society. They are places of love, where we are bonded in love, with Jesus at the centre. Very beautiful. Very simple. It's very little. This littleness comes from God. It is the mystery of Bethlehem.[47]

Marie-Hélène Mathieu identifies the various dimensions she sees as epitomising the gift of Faith and Light.[48] The first dimension is the mystery of the presence of Jesus hidden in the hearts of those with disability (Lk. 10.21; Mt. 11.25). She believes the mystery of which Jesus speaks is the mutuality and reciprocity of the love between Father and Son through the Holy Spirit. People with an intellectual disability reveal the Trinity (M.-H. Mathieu, personal communication, September 24, 2002). The second dimension is the value of prayer. The third dimension is Faith and Light as a place of communion, which requires commitment to one another from its members. She reiterates that trust in God and committed friendship are fundamental to community life in Faith and Light.[49]

The Beatitudes, which Vanier terms "the charter of love," underpin the spirituality of Faith and Light. "In order to live love, we need to receive love, which implies a certain poverty and a surrender to God" (1999, p. 12). Vanier emphasizes the need for rest and inner silence to facilitate the receiving of love. He thereby affirms the contemplative dimension in living the spirituality of Faith and Light.

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[47] Vanier made these remarks in an unpublished address entitled *The gift and the mission of Faith and Light* delivered to the Faith and Light International Conference in Warsaw, Poland on July 22, 1994.

[48] Mathieu outlined these points in an unpublished address entitled *The handicapped person, his call at the heart of Faith and Light* delivered to the Faith and Light International Conference in Warsaw, Poland on July 23, 1994.

[49] At a conference entitled *Faith and Light today* given on September 23 2002 at the Faith and Light International Conference in Rome.

Mission

Vanier describes the mission of Faith and Light as being a place of healing and reconciliation.[50] The work that God effects through intellectual disability in Faith and Light is the healing of hearts and reconciliation with one another in love. Vanier describes Faith and Light as a sign of hope in a broken world. He believes that the treasure of Faith and Light is its shared life with people who are vulnerable (1999, p. 5). The mission of Faith and Light is to witness to the importance of those who are vulnerable as a "source of communion of hearts."[51] Faith and Light believes that those who are vulnerable are "indispensable" and deserve to be treated with "greater honour... greater respect" (1 Cor. 12.22-23). Their place is not at the periphery but at the center of community life.[52]

Faith and Light recognises and celebrates the giftedness, the value, and the belovedness of people with an intellectual disability. It encourages people to commit themselves in friendship, or to form "covenant relationship" with, other members of the community group. "Our goal is to treat each person with respect and love, as a unique human being; to listen to each one and to help each one become more fully him or herself, in an environment of mutual friendship and trust" (1999, p. 9). Ghislain du Chene in the *Guidelines 2001-2002* captures the "essential mission" of Faith and Light:

> to witness to the world to the beauty and vocation of the mentally handicapped person, to bring to the parents hope and support, to open to the friends a way of friendship and commitment towards the weakest (2001, p. 108).

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[50] Vanier relies on a reading of Johannine theology which frames disability as a means through which God's glory might be revealed in a person's life (Jn. 9.2-3). His remarks come from an unpublished address entitled *The gift and the mission of Faith and Light* delivered to the Faith and Light International Conference in Warsaw, Poland on July 22, 1994.

[51] Vanier (1999, p. 11) cites the witness of St. Lawrence in 258 CE who, when commanded to give the wealth of the churches in Rome to the Roman authorities, arrived with the poor of the city, proclaiming "The poor are the treasure of the Church."

[52] Mathieu (1994) maintains that part of mission is to reinstate people with disability to their position at the heart of the Church, a position confirmed in the Roman Catholic Church by Pope John Paul II.

Role of Suffering

In the September 2001 *Guidelines*, Vanier writes,

> Faith and Light is founded on suffering. It was born out of the suffering of parents and their children. It desires to be a response to suffering. But this response is always inadequate... (p. 15)

Faith and Light seeks to provide comfort to the suffering of people with an intellectual disability and the suffering of their families. People with an intellectual disability can experience physical pain, and the psychological and emotional pain of rejection. Families can experience the pain of isolation, and of shame and guilt.[53] Vanier calls people to place themselves in front of their own pain and the pain of others. He warns against lapsing into depression, guilt or overactivity in response to suffering. "We all have to situate ourselves in front of the suffering we encounter in and around us" (1999, p. 18). Vanier acknowledges the difficulty of the task given that society seeks to avoid suffering at all costs, especially in relationships. Despite the increasing sophistication of society, suffering remains a given of daily life.

Vanier acknowledges that Faith and Light is not the only response to the pain of a person with an intellectual disability or that of a parent or sibling; nor does it hold itself out as the only response to the universal suffering of humankind. It is a community that might bring some relief to a few people who suffer. "In and through our communities they may begin to accept themselves, to have friends, to find a meaning to their lives and even a certain *joie de vivre*. Many, however, still live in pain" (1999, p. 19). He acknowledges the difficulty of remaining close to people in anguish for whom one is not able to provide relief. Vanier also acknowledges that psychological pain can be more difficult to bear and to treat than physical pain. He advocates the presence of another as a response to suffering of this nature. The presence of a friend communicates that the person is not alone. A friend can reveal and call forth the beauty in one who hurts, and re-awaken a

[53] Vanier clarifies this point in a video documenting the 2001 pilgrimage to Lourdes. There he reflects that that he often hears sadness expressed at the sight of people with an intellectual disability. He advocates helping others to see that the real sadness is the *rejection* that people with disability suffer.

desire to live (1999, p. 19). "Our communities are there to help each person live through sufferings and persecutions" (2001, p. 57).

Compassion

Compassion is fundamental to the spirituality of Faith and Light. The communities are founded on the suffering of people, and people are called to serve others through a willingness to "suffer with" (*com* – with; *passio* – to suffer) them. Vanier differentiates between different forms of compassion. Compassion involves developing and using competence to alleviate suffering of others; it also involves the ability to "be with" or "suffer with" others where there is nothing that can be done to ease the pain. The latter form Vanier terms compassion "in the strongest sense of the word" and describes it as "the heart of L'Arche and Faith and Light."

> I am not ignoring the importance of celebrations in L'Arche and Faith and Light or all the joys of communion between us and I do not want to be pessimistic. But the experience of these 34 years in L'Arche has shown me that in order to be faithful on a long-term basis and to be committed to working for unity, we have to learn how to remain close to suffering, to hold on in situations of pain. We have to discover compassion. Jesus puts compassion at the heart of the new life he came to bring (Lk. 6.36) (1999, p. 21).

Concept of the Human Person

Vanier emphasizes the significance and the uniqueness of each member of Faith and Light, as a beloved child of God. He encourages communities to reveal the giftedness of each member, and to enable members to own and to share their giftedness with others. Vanier believes that the human heart is the place where the human and the divine embrace each other. In Faith and Light communities, members are called to grow in depth and openness of heart to become a source of love for wider society. What does Vanier mean by "openness of heart?" It begins with an awareness of one's own value and dignity as a human being, and a trust in one's capacity to be a source of life for others. The awareness and the trust grow through being loved, appreciated, and rejoiced in by others. Faith and Light for Vanier is first and foremost a "school of love," where

members have a personal encounter with the God of Love, who reveals to each person, "You are my daughter, my son, the Beloved; with you I am well pleased" (1999, p. 10).

Vulnerability and Communion

The spirituality of Faith and Light promotes growth in love through communion with the person of Jesus Christ hidden in the hearts of those who are vulnerable and those who suffer. Vanier distinguishes "doing something for" people with disability from "being with" them. Communion is being with another, and a willingness to enter into a relationship of mutuality and reciprocity that reflects and incarnates the interrelatedness of Godself in the Trinity. Communion expressed through friendship is one of the prinicipal ways in which the spirituality is lived.

Vanier (2001) re-iterates that God is Love.

> God is not simply the creator of heaven and earth or the supreme judge. He is someone who loves. He is Love. To be sure, Love protects, watches over another, educates him. Is not this what makes a father or a mother? But above all, Love is communion, vulnerability, mutual belonging. "You are mine, and I am yours." This belonging is a relationship of mutual trust. It is a covenant. Love does not impose itself; it calls, it invites, it attracts towards communion. Love only exists where there is freedom. It is mutual gift (p. 35).

Jesus reveals the vulnerability of God. "He was born little and poor." Vulnerability is fundamental to communion. "To live in communion with someone, one must be small and be able to show oneself as weak" (p. 35). Vanier defines communion as "reciprocal vulnerability."

Community

Faith and Light is a *community.* Relationship health is vital and people are called to express their love by caring for, and praying for one another. Vanier believes that the first Christian communities were a response to Jesus' command to "love one another as I have loved you." They serve as a model for Faith and Light communities. The essence of community life is the sharing of hearts with one another.

> The communities are united by the same life which circulates in each heart. The life is the life of Jesus and the Holy Spirit which is given to us... This is the essential thing: to care for the well being of each person and for the unity of the whole; not to think ourselves superior to others, but to serve them and to seek their good (2001, pp. 42-43).

Vanier believes that community life bears witness to the truth of the Beatitudes.

> It is the quality of our community life which gives authority to our words and which calls others to know Jesus and the love which he pours into our hearts. "It will be known that you are my disciples by the love you have for one another" (Jn. 13.35) (2001, p. 50).

He suggests practical means for building community, particularly with those whom others find difficult: take an interest in them; do small acts of kindness for them, "little actions full of affection and deliberate attention;" and pray for them (2001, p. 69).

Vanier regards the community life in Faith and Light as the lived expression of the parable of the marriage feast or great supper (Mt. 22.1-14; Lk. 14.16-24). It is the poor, the crippled, the blind, and the lame who feast at the "banquet of love," when the invited guests make excuses for attending. Faith and Light is a banquet of love, prepared in particular for those whom society marginalizes. Therefore Vanier challenges members of Faith and Light communities to welcome people from different backgrounds. He emphasizes that once the people with an intellectual disability arrive, it is a celebration for *all* people.

Communion with Jesus Christ remains the source or the lifeblood of community life in Faith and Light. Vanier emphasizes the need for each community to immerse itself in the love of Jesus. This is the power of its attractiveness. "It is life which communicates life." Vanier encourages the leaders of the Faith and Light to shepherd the communities in such a way that the communities be as *alive* as possible.

Authority

The metaphor of shepherd is integral to Faith and Light's understanding of community authority. The movement models leadership on the image of Jesus as the Good Shepherd (Jn. 10.1-18) who is both gate and shepherd for the flock. The emphasis in leadership is on knowing the needs of the flock and responding accordingly, and on giving direction. O'Reilly (n.d., p. 4)[54] recalls in Jesus' commission to Peter that it is clear that the sheep belong to Jesus, and therefore leaders work *with* Jesus Christ, and not *instead of* him. "Feed *my* lambs... Tend *my* sheep... Feed *my* sheep" (italics mine) (Jn. 21.15-17). Lacroix (n.d., pp. 12-13) argues that all those charged with the well-being with others in Faith and Light, not merely those exercising religious authority, are called to model their leadership on Jesus Christ as the Good Shepherd.

Vanier (1984) clarifies that the shepherd needs to know each sheep "by name," recognizing each individual's gift and call or mission. Shepherds or leaders are bonded in love to each member, and are willing to put each person's needs before their own personal interests. As well as loving members and tending to their growth, leaders are called to organize and to animate community life. Leaders need to recognize that Scripture reveals consistently God's choice of broken people as leaders of God's people (Moses who had murdered, Peter who had denied, Paul who had persecuted). Childlike trust in God to provide guidance and support in times of need is essential for leaders. It is the Spirit of God that enables leaders to remain "young, open and full of wonder" (p. 6). Przeciszewski (n.d., p. 17) reminds leaders in Faith and Light that responsibility is a ministry given only for a specific time. As a gift from God, leadership needs to be exercised in union with God. It requires maturity for leaders to discern between God's will and their own will in any situation.

Vanier calls leaders to exercise authority as "servants of communion," facilitating communion between members, and seeking communion themselves with God and with

[54] Page references in this section unless otherwise indicated are to the booklet compiled by the Formation Commission of Faith and Light International entitled *Sharing Our Responsibility in Faith and Light.* It is undated.

people. They carry a two-fold mission of fostering the growth of members' in love and truth and of keeping the community true to its fundamental aims and vocation as defined in the Charter and Constitution. After the model of Jesus Christ, leaders are *humble* servants of communion (cf. Jesus washing his disciples' feet – Jn. 13). It is the most vulnerable, before those in authority, whom God chooses as most precious in God's sight. In Faith and the Light the most vulnerable form the heart of community life, and their growth in love and truth is the community leaders' priority. Vanier is clear that the interests of the individual come before those of the community. Community forms around people; people are not formed to fit community (p. 8). The leader exemplifies and promotes unity. Leaders embrace conflict rather than avoid it, and work for reconciliation. In Faith and Light leaders need to share their responsibility. Community life thrives on all members being able to share their gifts with one another. Leaders with compassion, firmness and vision empower others to exercise their gifts (p. 9).

There are peculiarities associated with leadership in the Faith and Light movement. Faith and Light communities are borne out of suffering, and members are called to be present to one another in their suffering. As Le Polain (n.d., p. 20) notes, leaders therefore need to be willing to share in the sufferings of community members, particularly the pain of rejection. It can only be done in the strength that God provides.[55] Faith and Light advocates companionship as a response to suffering. Leaders as with any other members need a "true friend." They need to seek the practical support of the coordinating team and to work for unity in the coordinating team[56] and in their own inner lives. Marie-Hélène Mathieu views crisis arising from conflict in Faith and Light communities as an invitation to approach unity in a different way.

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[55] She continues to list some of the challenges leaders face: lack of involvement of young people; stagnation in community life; conflict between members of the community; challenges in balancing responsibilities in other domains of life; loneliness; personal lack of commitment; criticism; loss of direction (p. 21).

[56] This was an aspect that Maria-Cecilia Buckley emphasised in an unpublished address entitled *The role of the coordinator* delivered at the International Meeting in Rome on September 25 2002. She spoke of the need for coordinators: to recognise the multiplicity of gifts that exist in the coordinating team; to work at various levels; to "meet" others; to share and delegate responsibilities; to develop a global vision; to be an agent of unity, through listening and arriving at consensus; and to assume responsibility, defined as "responding to need."

Vanier emphasizes the need for inner peace, wellness and rest in those called to exercise authority. He distinguishes between the cross leaders are called to carry and those they are called to set aside. He links love for self with love for others. Both find their source in remaining in communion with the love of Jesus Christ (Jn. 4.13-14; Jn. 7.37-38; Jn. 15.5).[57] "The unity between our heart and that of Jesus, and between our heart and that of others is something very simple" (p. 31). The unity invites a harmony between being active and being passive; giving and receiving; speaking and listening; doing and being; being the "shepherd" and being the "lamb." He calls for leaders to begin the interior pilgrimage, in order to discover the hidden treasure within them.[58] Vanier reminds leaders that they did not choose Faith and Light, so much as Faith and Light chose them. Vanier is insistent that members let go the idea of hierarchy in a Faith and Light community. Faith and Light organizes itself as a circle not a pyramid, where each member has an equally important role to play.

Discernment is a key word in the election of leadership in Faith and Light. It connotes that selection of leadership is communal, prayerful and respectful. It is a process of open dialogue around predetermined questions that reflect on the history of the community, on the community priorities at a given time, on the qualities sought in a leadership, on the particular gifts and growth areas of nominees (while nominees are absent), and on ways in which a community can support the elected candidate. It is a process that is consistent

[57] This is a theme in exercising authority that Vanier re-iterates. Vanier speaks of the inevitable loneliness of leaders. In their solitude it is essential that leaders take responsibility for nurturing their own relationship with God as a means of exercising authority in the strength and wisdom of God. Leaders need to balance their responsibilities in the Faith and Light communities with responsibilities they carry in their personal and professional lives. He also calls leaders to find a balance between under-functioning and over-functioning in exercising authority. "True authority enters into dialogue, gives general directions and ideas, and then leaves others to fulfil their responsibility and to get on with the job" (n.d., p. 10). An evaluation needs to occur afterwards.

[58] Vanier offers pointers for the journey to inner unity: be clear about one's motivations; make provisions for one's own needs; take time to rest occasionally; discover one's own rhythm and style; find a map or a guide; travel with others rather than alone; find the courage to make a decision and not lament over other options not taken; allow oneself time. He calls for self-knowledge on what is life-giving for one's heart, body and spirit and to take responsibility for nurturing oneself. He emphasizes the need for sound spiritual accompaniment and nourishment. "The greatest gift I have received is to have met a Dominican priest who has been my guide for forty years" (n.d., p. 36).

with the tenor of mutuality and calling forth of gifts that inheres the spirituality of Faith and Light.[59]

Some Spiritual Practice Features

In 1988 the International Council of Faith and Light established a Formation Commission. The mandate of the Formation Commission was to reflect on means of formation and to publish their reflections in a series of booklets drawing on the experiences of individual communities. The goal of formation in Faith and Light is the growth in members' relationship with Jesus Christ and in their fidelity to the movement's vocation. The booklets serve as a valuable resource for understanding some of the distinguishing features of spiritual practices in the movement. In the following section I outline some of community's spiritual practices discussed in the booklets.

The Annual Guidelines

The *Annual Guidelines* appeared soon after the pilgrimage to Lourdes in 1971. They serve to nourish the spiritual life of both Faith and Light communities and their individual members, and promote unity and communion amongst the communities scattered around the world. For example they encourage member communities to pray for one another, especially for new communities. They help to form the coordinating team in the spirit of Faith and Light, and serve as a practical resource for preparing the monthly meetings. They include material for the three dimensions of each meeting: welcome and sharing, prayer, and celebration and the meal.

The *Guidelines for the First Year* emphasise that the materials given are suggestions only. The coordinating team needs to seek the Holy Spirit's guidance in adapting the proposed resources for each meeting to the specific situation and context of the

[59] The essentials of the process hold across local, national and international levels. The local community conducted a discernment for a community leader at its February 2002 meeting; the national community discerned its national coordinator at the annual meeting held in Saskatoon in August 2002; the International Meeting held in Rome in September 2002 elected an International Coordinator and Vice-Coordinator.

community. The culture, the composition and the age of the community will be significant factors in planning. The *Guidelines* suggest flexibility in establishing the shape or pattern of the gatherings, and use of the liturgical calendar in planning to enhance community life. Marie-Hélène Mathieu in the *Guidelines 2001-2002* encourages the coordinating team to use creativity in planning the meetings. In the first year of a community's life, there are themes suggested for ten gatherings divided into two categories: "Jesus loves us;" and "Jesus calls us to live in community." The themes under the first category include God's love for, and God's call to each person, Jesus' presence in "little ones," Jesus' ability to heal hearts, and the suffering of humanity. The themes under the second category include God's call to be together, community as "body," the gifts each member brings, community as a place of growth, and the worldwide family of Faith and Light. The *Guidelines* serve as a means of forming communities in the spirit of Faith and Light.

The *Guidelines* also contain practical suggestions for enriching community life. The *Guidelines for the First Year* emphasise making members feel welcome and special (n.d., p.18). Therefore, it is important community members know the names of each other and that they name their community (p. 52). They note that singing can be an important way of expressing community life (p. 28). They promote companionship as the principal response of Faith and Light to suffering (p. 33), remind members that the bond between community members is Jesus Christ (p. 41), and they encourage communities to deepen their life through giving members specific responsibilities which enable them to exercise their gifts (p. 46).

The *Guidelines* seek to deepen the spiritual life of the community and of individual members. For example, in the *Guidelines 2001-2002* Vanier has written reflections on the birth and the growth of the Church as recorded in the Acts of the Apostles. These reflections form the basis for the sharing time during which the coordinating team allows Holy Scripture to penetrate the hearts of members and gently transform their lives. The international chaplain Father Joseph Larson has made suggestions for silent prayer of the heart, "the prayer of the poor person," for the prayer time in the gathering. He cites the

words of Psalm 131[60] as an example of the prayer of poverty, where the psalmist is content to be held like a child in her mother's arms, communicating trust not through words but through allowing herself to be held. The *Guidelines* also propose that each community set aside one day each year to announce and to share the mission of Faith and Light.

The Coordinating Team

The *Guidelines for the First Year* emphasise the role of the coordinating team in developing and animating community life. The team meets to evaluate previous gatherings, to prepare for future gatherings and to ensure that the community remains true to the spirit of Faith and Light as expressed in the Charter and Constitution. Parents, friends, the chaplain and the community leader, who facilitates the meeting, make up the team. It usually numbers between four and eight people, and meets between the monthly gatherings to evaluate the past meeting and prepare for the next. The team carries the vocation of Faith and Light, and keeps each community to the particular mission and goals it has set for itself. The *Guidelines 2001-2002* recommend that the coordinating team be intentional about creating and maintaining unity within itself, which is in turn reflected in the community. Coordinating teams may meet for an extended period each year as a means of promoting unity.

Personal Testimonies or "Fioretti"

"Fioretti" in Italian is a bouquet of little flowers. An important feature of the life of Faith and Light is the telling and re-telling of stories. The booklet, *Faith and Light Fioretti,* presented on the occasion of the Faith and Light International Meeting in Quebec in July 1998 is a collection of personal experiences of members, intended to comfort, inspire and to share wisdom. The stories serve as a means of shaping and sharing the spirituality of Faith and Light, where Fr. Larsen defines spirituality as "the dream we want to realize in

[60] "But I have calmed and quieted my soul, like a weaned child with its mother; my soul is like the weaned child that is with me" (Ps. 131.2, New Revised Standard Version).

our lives" (1998, p. 3). Unique experiences of friendship are one manifestation of the spirituality of Faith and Light. Fr. Larsen believes that stories have a capacity to evoke reactions of the heart, and contain a transformative power enabling people gradually to live what the stories recount. It is where miming Gospel passages can have a dramatic effect on both participants and observers.

The story of the beginnings of Faith and Light at Lourdes is one that not only transformed the original pilgrimees; it also has transformed and continues to transform later generations. The story carries the essentials of the spirituality of Faith and Light, and it is a story that the community keeps alive by retelling and re-enacting. Fr. Larsen encourages people to choose those stories they want to listen to from among the many stories that saturate them, and to take time to reflect on those "rare moments" contained in the stories. He encourages members to be attentive to the "rare moments" that occur in their own lives, and to share the story of those moments with the community at a gathering. Story-telling remains an important means of enriching community and personal life in Faith and Light.

The stories contained in *Fioretti* record significant shifts in perspective in the hearts and minds of parents. They document the depth, the richness and the sensitivity of the spiritual lives of people with a disability. They witness to the psychological and emotional healing that people with and without a disability have experienced through friendship in Faith and Light. They recount what members have learned from people with a disability, and they testify to the ability that relationship with people with a disability has to transcend religious and cultural barriers.

Prayer Life

Faith and Light seeks in its corporate life to respect and reflect the active and contemplative dimensions in Christian discipleship. It gives attention to its need and its call to pray as a community (see Appendix B for the Faith and Light Prayer).

Prayer suggestions.

A booklet on suggestions for morning and evening prayer for use at events other than community gatherings such as meetings, retreats, and summer camps appeared in 1997. The booklet suggests that attention be given to the place, the time and the content and format of prayer times. It recommends a single theme, with times of silence, a reading from the Bible, and some songs. It suggests appropriate music and opportunities for intercessory prayer and non-verbal forms of prayer. The booklet emphasizes sensitivity to people of different faith traditions or denominations. The different formats proposed include liturgies that are meditative; that invite antiphonal singing; that follow the liturgy of the Divine Office in the Roman Catholic tradition; that focus on use of a symbol; that use a significant event in the life of the group; and that are intended to take place outside in nature.

Retreats.

Community retreats convey what Faith and Light believes about God, about people with disability and about relationship. Retreats for people with an intellectual disability take place because of the movement's belief in the capacity of these people to grow in their spiritual life. Mgr Marcel Gaudilière (1991) in the booklet *Deepening our Spirituality in Faith and Light* encourages Faith and Light to foster the spiritual growth of people with an intellectual disability by helping them to recognize the wonder of God around them, by praying with them and sharing in the Eucharist, by enacting Gospel passages together, and by encouraging them to be more concerned for others (pp. 14-17). Retreats can foster such growth by providing spiritual guidance and nurture to people with disability. They are also a means of keeping spirituality at the center of community life.

> [I]t is the weak-handicapped in the eyes of the world who can call us most authentically into community, into a love that is sacrificial and Eucharistic, into being the Church of Jesus, and ultimately into the God, who as Trinity is the first and final Community of all humankind' (1989, p. 3).[61]

[61] Page references in this section unless otherwise indicated are to the booklet compiled by the Formation Commission of Faith and Light International in 1989 entitled *Retreats in Faith and Light.*

Faith and Light retreats seek to create an atmosphere conducive to a personal encounter with Jesus Christ for the retreatants. They encourage people to listen attentively to God, and to be open to conversion of heart, a prerequisite to spiritual growth. The spirituality of Faith and Light that infuses the retreat emphasizes the "treasure hidden in the heart of the poor," namely their simplicity of heart and their ability to trust and depend on others. The retreats emphasise the vocation of people with an intellectual disability in revealing that God has chosen vulnerability (cf. 1 Cor. 1.27-28; Phil. 2. 6-11), and that all humanity shares a brokenness at a profound level of being. They call retreatants to be the sacrament of God's presence in Jesus Christ to one another, to be intentional about befriending others, especially those who are the most vulnerable, and to allow them to create community. The retreats promote the positive contribution of ritual and liturgy in bringing order to, and creating meaning in, daily living. Ritual helps people to face the unfamiliar, to remain grounded, and to find rest. The liturgy on retreats needs to be inclusive and respectful of the needs of all retreatants. It also provides a means of translating the retreat experience into daily life. Examples of themes used at Faith and Light retreats include: "The Prodigal Son;" "Being Friends;" "The Poverty of Jesus;" "We Are Hurt With Jesus, With Jesus We Are Healed (the Paschal Mystery);" "Christmas;" "Creating Bonds."

Faith and Light emphasises not only the content of what is spoken at retreats, but the manner in which it is delivered. People with disability will relate to the heart of the speaker, where they may not understand the words being used. It is important that there is ample time at retreats for non-verbal means of receiving and expressing the message through music, ritual, drama, symbol, creative activities, movement such as walking, through interaction with nature and through silence.

Community Celebration

The publication of the booklet *Let's Celebrate Our 25th Anniversary* is an example of the way in which the Faith and Light movement seeks to promote the life of its local communities. The proposals in the booklet encourage members to reflect on the history of

their community, to give thanks for their community life, to seek forgiveness where love was lacking, to celebrate their God-given unity and to promote their mission. They call communities to greater fidelity and to be more mission-oriented, to witness to God's work in their lives through shared stories, and to generate renewed enthusiasm in their community life.

The booklet suggests programmes for a community weekend of revitalization incorporating the dimensions mentioned above. The weekend includes: song; retelling the story of the beginnings of Faith and Light; reflecting on the Faith and Light symbol, and the banner and the name of the local community; and discussing each member's personal call, and the country's call to Faith and Light, and expressing it through art. There is reflection on the four times in Faith and Light (prayer, sharing, celebration and the fourth time), and communal liturgies of healing and reconciliation, and of thanksgiving for the gift of Faith and Light. There is also opportunity for looking to the future with goals for community or personal growth, for community and individual mission. The weekend concludes with a commissioning or recommitment ceremony.[62]

The Faith and Light movement devotes time and energy to exploring ways in which community life can remain vibrant and rich. One of the charisms of the community is celebration, and milestones provide an opportunity to rejoice together. Faith and Light is aware of the importance of institutional structure that enhances the community's charisms. The preparation for celebrating a significant anniversary demonstrates how the various levels of the structure work together to facilitate life and growth in the movement.

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[62] There are follow-up meetings suggested. A one-day meeting is held later in the year to evaluate progress towards goals set at the weekend for community and personal growth, and to gather personal stories of growth ("fioretti"). Community leaders later meet at an area, regional or national level, to prioritise the needs identified at the community weekends and to establish plans for meeting those needs. These leaders meet a second time to finalise arrangements for the 25th anniversary pilgrimage or celebration, to evaluate the implementation of the plans set at their earlier meeting, to gather personal stories of growth for the fioretti, and to plan for the following year.

The Ecumenical Vocation

The Faith and Light International Council published the booklet *The Ecumenism in Faith and Light* in February 1998. In June of the same year, the Faith and Light Ecumenical Commission produced two booklets: *Ecumenism – A Gift of Friendship*; and *Ecumenical Guidelines*. The booklet from the International Council explores the history of ecumenism in Faith and Light, and it offers guidelines on living ecumenism in community gatherings, formation sessions and international meetings.

The History of the Vocation

Faith and Light's ecumenical vocation was foreshadowed by the presence of a group of Protestants and Anglicans on the 1971 pilgrimage to a Roman Catholic shrine. After the pilgrimage, communities continued to meet together in their own localities, where people from denominations other than the Roman Catholic Church joined in the celebrations. Sometimes the gatherings included a Roman Catholic Mass. Faith and Light regarded Pope Paul VI's welcome of the 12 000 pilgrims to St. Peter's Basilica in Rome in 1975 as a confirmation of its vocation in the eyes of the Roman Catholic Church. In this formative stage, Faith and Light understood itself as a Roman Catholic movement, even though it held no recognized status with the Roman Catholic Church.

Non-Roman Catholic members of Faith and Light desired to form communities within their own denominations. Communities with affiliations with the Anglican Church began in England, with the Presbyterian Church in Scotland and with the Methodist Church in South Africa. Communities with ties to the Orthodox tradition have sprouted in former Eastern European countries. The leaders of Faith and Light began to recognize that the movement was an interdenominational one, and they changed the Charter and Constitution to reflect this reality. It still requires tolerance, sensitivity and creativity to plan community gatherings, formation sessions and international meetings that respect the needs and desires of all members, particularly those belonging to minority groups. The reality is that tension and pain are inevitable. Faith and Light recognizes that its

ecumenical vocation is ancillary to its primary goal of welcoming people with disabilities, their families and friends within Christian communities, and encouraging their growth in truth and love. It lives the tension as an international movement that both promotes the integration of its members in and with their own local faith communities, and at the same time unites all the members as an international family.

The Development of the Vocation

The International Council created an Ecumenical Commission for the Northern European Zone in 1992 which expanded to become an international commission, charged with ensuring that the international documents reflected Faith and Light's ecumenical vocation. The International Council has taken the initiative to include non-Roman Catholic denominational leaders at international meetings. In 1990 at Edinburgh, the Scottish Episcopal Diocesan bishop celebrated the Eucharist, and in 1994, at Warsaw, the Orthodox Metropolitan of Brichaunt, Bishop Teofan Sinaitul spoke on Orthodox spirituality. The movement continues to recognize and to live the pain of division. Its response remains to foster personal relationship and dialogue between members of different denominations and faith traditions. It encourages at all levels "a communion of hearts."

Faith and Light states clearly in *Ecumenism in Faith and Light* (1998) that the movement does not set out to be another church. Rather it calls its members to discover the gift and the beauty of their own denomination (p. 16), and to grow in truth and love within their own church. Ecumenism in Faith and Light emphasises sharing one another's gifts, and mutually enriching one another, rather than transcending barriers. It acknowledges difference, while it proclaims that that which unites is greater than that which divides. The particular contribution of Faith and Light to the ecumenical movement is its emphasis upon welcome of the other, and upon recognising the presence of Jesus Christ in the heart of the other. This leads to a "communion of hearts," where members are able to fulfil Jesus' command to "love one another, as I have loved you" (Jn. 15.12). Faith and

Light calls for deep respect of the dignity of others and their traditions, for acceptance, for openness, for humility and for mutual forgiveness.

The document *Ecumenism in Faith and Light* (1998) calls attention to the ways of living ecumenism in different types of community: those where members all belong to the same denominational church; those based in one denomination, which welcome members from other churches; and those which are interdenominational. The document bids members to pay particular attention to the interests of those from minority churches at formation sessions, retreats, zone meetings and international meetings (p. 25).

The *Ecumenical Guidelines* (1998) acknowledge that for some people Faith and Light might be the only contact they have with the Christian Church. The booklet gives practical suggestions on respecting religious differences at regional, national and international meetings. It sets out brief sketches of the beliefs and practices of several Christian denominations, and their respective understandings around the Eucharist. There is instruction on blessing during the Eucharist for those not able to receive the elements. The booklet gives examples of non-Eucharistic liturgies in Faith and Light meetings (pp. 31-41). Sometimes meetings might have a Roman Catholic Mass and a Protestant Eucharist.

Fr. Joseph Larsen in the booklet *Ecumenism: The Gift of Friendship* clarifies that the task of the Ecumenical Commission is "to make the shared presence of Christians of all denominations a source of joy rather than a source of pain and conflict" (p. 5). He writes later in the same booklet that ecumenism "begins with friendship" (p. 23). It is about the heart before it is about a set of doctrines. It requires *kenosis* or self-emptying, which connects people with the mystery of the oneness of Jesus Christ and the Father (Jn. 17.11, 21-23). Another writer in the same booklet writes of the pain members experience in being prevented from sharing fully in the Eucharist: "[B]ut we would rather be together and experience the pain of division from time to time than be apart" (p. 26). Another author in a similar vein notes, "Maybe one of the things I have learned most forcibly is

that if we concentrate more on the things that unite us, then our differences will not prove such a barrier" (p. 34).

The Washing of Feet

Jean Vanier believes that unity is at the core of Faith and Light's vocation. This unity finds expression in the Charter. "Faith and Light believes that the person who is weak and handicapped can become a source of unity in society and in the Churches and also between Churches and the nations" (I, 5). Faith and Light embraces an ecumenical vocation. It recognizes the pain that arises from the barriers to sharing together in the Eucharist. Therefore Vanier has chosen to emphasise the sacramental nature of Jesus' gesture recorded in John 13 of washing his disciples' feet. The community re-enacts the gesture liturgically, an event in which members of all denominations are able to participate fully. I have included a sample liturgy prepared for the Canada West Provincial Meeting in August 2001 in Appendix C. Vanier (2001) believes that the gesture emphasizes the humility, the forgiveness, the service of others, the simplicity and the tenderness, which lie at the heart of Faith and Light's values.

Usually the symbolic action of foot-washing takes place with people seated in a circle or circles depending on the number taking part. In the centre of the circle will be a jug of water, a basin and towels, a Bible and a candle. The celebration often begins with the lighting of the candle and the singing of reflective songs to invite inner stillness. The celebrant will explain the meaning of the ritual and will read or have someone else read the relevant passage from the Gospel of John (13.1-17). The celebrant proceeds to kneel before the person on her or his right and to wash the person's feet slowly and with deep reverence. The celebrant wipes the person's feet and waits kneeling as the person places hands on the celebrant's head, and the two pray in silence for several moments. This reflects the mutuality and reciprocity in the gesture. The person gets up and turns to the person to the right and repeats the gesture of kneeling, washing, wiping and praying. The process continues until all members have had their feet washed. Gentle chant of a refrain or meditative music accompanies the ritual. The celebrant assists any person having

difficulty with the ritual. In some instances a person may prefer to have washed her or his hands. When the washing of feet is complete, members in the circle share their reflections on the ritual and how it contributes to their understanding of unity. The celebration may conclude with the Taize chant *Ubi caritas* and the joining of hands as the group says together the Lord's prayer.

Directions for the Future

The number of countries in which Faith and Light is present has grown from 15 in 1971, to 23 in 1981, to 62 in 1991, to 73 in 2001. A progress report compiled in 1992 records the significant growth in numbers of communities and probationary communities which can occur after a pilgrimage: from 827 in 1990 to 989 in 1991. The growth appears to be taking place primarily in economically deprived countries, where support services for people with disability are negligible. Communities in these countries may look to Faith and Light to provide services, for which it does not have the resources. The report identifies the changing attitude towards people with a disability in economically developed countries, where their lives before and even after birth may be threatened. Contraceptives and sterilization may be imposed upon women with an intellectual disability, and young women with disability may have their pregnancies terminated without their knowledge. The policy of integration of people with an intellectual disability into mainstream society can lead to the closing of special purpose institutions without provision for replacement services.

The 1992 report calls for a return to the fundamental aim of promoting the emotional and spiritual growth of people with disability. It identifies the need to accompany mature people with an intellectual disability who may have specific issues they wish to address with someone. It suggests that communities adapt to the needs of families with young children with an intellectual disability. It encourages communities to involve parents, especially fathers, by giving them responsibilities, and it highlights the particular needs of aged parents as they search for residential facilities for their adult offspring with an intellectual disability. The report suggests ways of supporting these parents, which

includes undertaking to maintain contact with their child after the parents die.[63] The report draws attention to the grief of siblings, and to the need of formation for young people to facilitate their entering into covenant relationship with people with an intellectual disability.

The 1992 progress report encourages friendship groups which meet between meetings. It promotes holiday camps, pilgrimages and retreats for building community life and deepening members' spiritual lives. It invites larger communities to consider planting a new community. It affirms the organizational structure that enables leaders to enjoy the support of a coordination team at local, regional, national, zone and international levels, and it promotes the use of prayer in the discernment process for new leaders. It reminds communities of their need to be integrated with a local faith community.

The report also reaffirms the ecumenical vocation of Faith and Light, calling for communities to take initiative at the grass-roots level, and it promotes solidarity as an outworking of covenant relationship. Solidarity may occur within communities, between communities in the same area (where some members may transfer to another group) and between communities in different parts of the world. Economically deprived communities contribute their faith, dignity, joy and simplicity, while communities in privileged settings offer financial support, efficiency and organization. The report calls for the latter communities to share generously. The report indicates the need for formation and for transformation of heart. Community retreats are a means of transformation, deepening members' commitment to Jesus Christ and to those in need. The report concludes by acknowledging the desire of some to commit themselves more fully to the vulnerable.[64]

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[63] It gives the example of Jean-Claude who was placed in a psychiatric hospital after losing his parents. Different families in the Faith and Light community now welcome him to their homes every other weekend.

[64] Marie-Helene Mathieu (1995), one of the co-founders, encourages Faith and Light to consider a number of questions in discerning its future direction (p. 32).

- How does Faith and Light promote the prophetic vocation of people with an intellectual disability, and assist them to live in the spirit of the Beatitudes?
- How does Faith and Light enable parents to recognize the vocation of their children with an intellectual disability?

Mapping the Spirituality of Faith and Light

By way of concluding, it may be helpful to locate the spirituality of Faith and Light within the broader canvas of Christian spiritualities. In this way, one is better placed to assess both the strengths and growing edges in this particular form of Christian spirituality. Michael Downey (1997) offers a grid comprised of seven focal points as a means of mapping a spirituality of Faith and Light (p. 120).[65] When exploring spirituality one's focus is on the Spirit of God, which Downey describes as the love of God indwelling, or inherent in, a human being, in tensive interaction with the human spirit. In order to access how the Spirit of God is at work in a particular context, Downey suggests focal points as a means of charting any given spirituality. The Holy Spirit interacts with the human spirit: (a) within a culture; (b) in relation to a tradition; (c) in light of contemporary events, hopes, sufferings and promises; (d) in remembrance of Jesus Christ; (e) in efforts to combine elements of action and contemplation; (f) with respect to charism and community; (g) as expressed and authenticated in praxis (p. 120). I explore briefly each of these focal points in the context of Faith and Light

First, Faith and Light as a movement has its roots in French Roman Catholic soil, a culture scarred by the Second World War. At the same time, Vanier was a French Canadian, with an Anglo way of thinking. From the outset, there was cultural diversity, with an accompanying respect for difference. The co-founders, Jean Vanier and Marie-Hélène Mathieu, in some ways adopted the role of father and mother of the movement.

- How does Faith and Light assist friends to enter into covenant relationship with people with an intellectual disability?
- How does Faith and Light empower people to discover Jesus' love and the love of others for them, and to give of themselves to others in response?
- What is the response of Faith and Light to those who would terminate the lives of people with an intellectual disability before and even after birth?

[65] Downey (1997, pp. 42-43) sets out four levels, at any one of which Christian spirituality may be said to function. What can be said about Christian spirituality bears on what can be said about spirituality generally. First, spirituality is an expression of the intrinsic capacity in human beings for self-transcendence. Second, spirituality encompasses everything that enters into the life of a person or a community, engaged in a quest for self-transcendence. Third, spirituality describes the way that a quest for self-transcendence is codified, be it in the form of Articles of religion, in liturgical formalities, or in artistic style, for example. Fourth, spirituality is an academic discipline. The term *spirituality* functions at all of these levels, and may mean any one of these, depending on the context in which it is being used.

The seeds of the movement lay in the suffering of the Proffitt family, particularly their experience of exclusion.

Second, L'Arche which had begun four years earlier in 1964 had a strong influence on the religious and theological tradition of Faith and Light through the thought and vision of Jean Vanier. The influence of Père Thomas Philippe, a conservative French Roman Catholic Dominican on Vanier's thought and vision cannot be underestimated, as Vanier himself attests in a pastoral letter dated August 2003. Both the worker/priest movement in French Roman Catholicism, and the idea of the church being the church of the poor, as expressed by Pope Pius VI, were probably formative religious factors in the evolution of L'Arche and Faith and Light. The spirituality of Thérèse of Lisieux, "the little way," where God may be known in and through devoted attention to mundane domestic tasks is an influence. While L'Arche and Faith and Light remain lay movements, the Roman Catholic tradition continues to exert a strong influence over both communities.

Third, the challenges that France faced after Second World War provided the socioeconomic backdrop to the significant events, hopes, sufferings and promises at the outset of Faith and Light. Perhaps there was also a sense that secular and religious institutions had failed to serve human beings well in light of war. It is notable that Vanier in founding L'Arche removed Raphael and Philippe, the first core members, from an institution at Claremont.

Fourth, Pope John Paul II has written in the Encyclical *Fides et Ratio* at paragraph 93 that the prime commitment of theology today is to understand the mystery of God's kenosis. Downey would say that the theology and the spirituality of L'Arche and Faith and Light anticipates this mandate. The primary Christological memory expressed in the movement is the kenotic or the self-emptying Christ. There is an abiding sense of God's compassion in the midst of the vulnerability and the brokenness of the human condition. God is understood as being present in and to humanity's woundedness without taking it away.

Fifth, there is a general sense in the spirituality of L'Arche and Faith and Light that the two aspects of action and contemplation are conflated. For Vanier, to behold the wounds of Christ in a person with an intellectual disability is contemplation. Frenzied activity and prayer divorced from service both indicate a lack of balance. It seems for Vanier that both dimensions of the spiritual life meet in the concept of presence – presence to oneself, to others and to God. It is in being fully present to the moment that one experiences the abundance of life that Jesus promises through his death and resurrection. It is in presence to vulnerability and woundedness, at an individual and a corporate level, to one's own suffering and the suffering of others, that one discovers "hope" (M. Downey, personal communication, October 20, 2003). Young (2002, December) refers to "a kind of contemplative mode of waiting on God with one another" that is fundamental to notion of presence in L'Arche/Faith and Light.

Sixth, in its understanding of charism and community, L'Arche and Faith and Light view brokenness and vulnerability as a gift that unites the community. Community life is ordered around the weakest member. Ford (2002, December) identifies mutual presence, service and friendship as the principal ethical charisms in the community. Finally, L'Arche and Faith and Light incarnate a Gospel praxis of peace and justice, sourced in the Beatitudes. By their origin both organisations are deeply rooted in the Roman Catholic tradition, yet they remain open to a range of other traditions. While L'Arche and Faith and Light have been criticised for an insularity, there appears to be an attentiveness to societal and global issues.

Summary

Faith and Light is an international Christian organization comprised of nearly 1500 communities in 75 countries that is founded on the suffering of families with offspring with an intellectual disability. It arose as a response to the exclusion that one family experienced on a pilgrimage in 1968. It seeks to enable offspring and their families to find a place within the Church and society. It centres on the mystery of God's Triune presence hidden in the hearts of those with a disability. Faith and Light recognises that

people with an intellectual disability are a source of unity. They have particular gifts to offer in the realm of relationship, which include tenderness, welcome and simplicity. They are "teachers of the heart." The movement advocates presence as a response to the suffering that lies at the core of its life. Presence in the form of faithful friendships is the organisation's principal response to the pain of intellectual disability. Faith and Light emphasises the importance of trust in God, and committed friendships amongst its members, which together form the basis of its community life.

Faith and Light community life finds primary expression in monthly meetings, which balance times of sharing, prayer and celebration. "Fourth time" or informal times of gathering with friends from the group between monthly meetings strengthen members' commitment to one another. The movement is not involved in the management of educational, therapeutic or residential facilities. It does seek to integrate itself with other organisations serving those with an intellectual disability, as it does with local faith communities. It embraces the Church's call to unity through promoting actively ecumenical initiatives.

The seeds for the first pilgrimage to Lourdes in 1971 out of which the Faith and Light movement grew, lay in the pain of Camille and Gerard Proffitt, parents of Loic and Thaddee. That was over 30 years ago in France. In this research project I explored the experiential world of a group of parents in Canada in 2002-2003. The parents were members of one local Faith and Light group. My purpose was two-fold. First, I wanted to understand better their lived reality, their joys and their challenges, as parents of offspring with an intellectual disability, with particular reference to the launching phase. Second, I wanted to assess the role of Faith and Light in their particular context. Having outlined the nature and the function of Faith and Light, in the next section I expand upon selected concepts from the social sciences that may help to explicate parents' reported experiences. I draw on research and theoretical literature in family systems theory, the individual, family and intellectual disability life cycles, stress theory, and grief theory.

Chapter Four

LITERATURE REVIEW

Intellectual Disability

There are many terms used to cover intellectually disability, such as mental or intellectual handicap, developmental disability or challenge or delay, and mental retardation. For the purposes of exploring the implications for the family, I have not considered it necessary to define the distinctions between different terminologies. I have used the term intellectual disability (hence "offspring with an intellectual disability") and based its definition upon that used for the US term *mental retardation.* Mental retardation is "an arbitrarily defined diagnostic category," whose meaning fluctuates according to prevailing clinical theory, and the social and political context (Marsh, 1992, p. 7). Essentially it connotes significantly below average intellectual functioning.[66] For the purposes of this study a diagnosis of intellectual disability requires significant limitations in intellectual functioning and in adaptive behaviour, and an initial diagnosis before the age of 18.[67]

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[66] Landesman and Ramey (1989; cited in Marsh, 1992, p. 7) trace four significant changes in its definition: (a) including adaptive behaviours; (b) reducing the cut-off for the intelligence quotient to IQ 70, or to two standard deviations below the mean of a test of general intelligence; (c) extending the upper age limit for initial diagnosis; (d) dropping the life-long duration requirement.

[67] There are four major systems for classification of mental retardation: (a) The American Association on Mental Retardation (AAMR) (formerly the American Association on Mental Deficiency), which specifies significantly subaverage general intellectual functioning with concurrent significantly impaired adaptive behaviour evident during the developmental period; (b) the American Psychiatric Association's DSM IV-TR system, which uses the above classification as well as a multi-axial system to classify additional relevant information; (c) the World Health Organisation's ICD-10 classification, which defines mental retardation as mental subnormality (an IQ of 70 or less), based on the current level of functioning regardless of nature or causation; (d) the developmental disabilities (DD) system, which is a functional rather than categorical approach and focuses on an individual's skills and the impact of the environment on use of those skills. The first three systems specify four levels of intellectual disability (a) mild (IQ 50/55 – 70), (b) moderate (IQ 35/40 – 50/55), (c) severe (IQ 20/25 – 35/40), (d) profound (IQ below 20/25). Intellectual disability professionals tend to use the AAMR system; mental health professionals favour DSM-IV-TR classification; people with a disability themselves prefer the DD system with its emphasis upon adaptive capacities rather than IQ scores (Marsh, 1992, pp. 8-11). For the purposes of this thesis, I have relied upon the AAMR definition given on its website:

Intellectual Disability and Families

Why focus on the family and not the individual with an intellectual disability in exploring the possible influences of the Faith and Light movement? There appears to be a trend in recent literature towards taking a family-focussed approach to explore the phenomenon of intellectual disability, especially from the perspective of clinical practice. There are several reasons advanced. First, families are often the primary care-givers, and the most consistent case-managers and advocates for their children. Second, families play an integral role in finding or developing the most conducive environment for their children. Third, families that are supportive and informed are a significant resource for children with an intellectual disability. Finally, given the stress and the demands these families carry, they need support, information and skills. Families are increasingly seen as part of the solution rather than part of the problem (Marsh, 2001, p. 3). From a strategic perspective, it made sense to explore the family. From a functional perspective the family is best placed to effect interventions. As will be seen in the following section, a systemic perspective reinforces the reciprocal relationship between intellectual disability and the family. Therefore, the focus of this enquiry was the role of Faith and Light in the life of the family, rather than in the life of the family member with an intellectual disability.

Intellectual disability impacts a family. A family will likely experience both challenge or burden and gift or benefit. Marsh (1992, pp. 14-16) differentiates between the subjective burden and the objective burden, with which families contend. The subjective burden refers to the emotional consequences of intellectual disability for family members. It

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Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. A complete and accurate understanding of mental retardation involves realizing that mental retardation refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. As a model of functioning, it includes the contexts and environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction of the individual with the environment, and the outcomes of that interaction with regards to independence, relationships, societal contributions, participation in school and community, and personal well being. American Association on Mental Retardation. (n.d.). *Definition of Mental Retardation.* Retrieved July 24, 2003, from http://www.aamr.org/Policies/faq_mental_retardation.shtml

includes the intense reactions parents often experience on learning of their child's disability, and in adapting to the reality. Many writers describe it as a grieving process, where family members mourn the loss of the child they dreamed of. Moreover, the deep emotions recur at various stages of the family life cycle. It can be a loss without closure, an ambiguous loss in Pauline Boss' (1999) terms. The objective burden refers to those tangible challenges families face on a physical, social, psychological, and economic level. They include challenges associated with offspring with an intellectual disability such as health issues, behaviour problems, sexuality and reproductive issues, and ongoing care. There are challenges as well for the families, which include caregiving responsibilities, financial demands, chronic stress, social stigma, marital and family conflict, sibling difficulties, and adverse effects on parental health. Against both subjective and objective burdens need to be weighed the gifts or benefits that families report: the strengthening of the family system; greater tolerance and empathy; opportunities for personal growth; enhanced appreciation of life; pleasure in the accomplishments of the family member (Marsh, 1992, pp. 15-16).[68]

It may be helpful to identify some of the needs families with members with an intellectual disability have reported. Broadly these families require information, skills and support, which include: caregiving arrangements for their relative; information about the disability itself, about interventions, and about resources and services; coping skills to deal with the presence of intellectual disability in the family; assistance with implementing interventions; guidance in adaptation as a family and as individuals; contact with other families; help in dealing with societal issues (Marsh, 1992, p. 16).[69] These needs vary in importance across the families' life-span.

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[68] There has been increased recognition of the gifts to family life that the presence of intellectual disability might bring, which include greater cohesion, increased *involvement*, and personal growth (Singer & Powers, 1993; Turnbull et al., 1993). Carter (1999, p. 264) identifies some of the benefits that accrue to families with a child with an intellectual disability: flexibility; group pride; and multicultural awareness. She urges families to fight discrimination and social stigmatization, and to be aware of their child's self-esteem levels, sense of competence and of belonging. She advocates that families be intentional about joining "communities of families like yours both for support and to counteract the negative effects of feeling stigmatized and alienated from the larger society" (p. 271).

[69] Walsh (1999, p. 323) emphasises the need for therapists to provide adequate information and guidelines for caregiving (including options for respite), and to promote contact with community agencies and other networks of support.

A Family System Perspective

Family systems theory sees the family as the context in which the phenomenon of intellectual disability is encountered. A family systems perspective casts families as organisms, which are interactive[70] and interdependent (Seligman & Darling, 1997, p. 5).[71] Families as systems are synergistic: the whole is greater than the sum of its parts.[72] System theory holds that where one starts in addressing an issue in a family's life is immaterial. Working with one of the elements in a system inevitably impacts other elements.[73] Structure and the process are two categories for understanding families. Circularity (in contrast to a lineal understanding) is the underlying concept of process, which recognizes the mutuality and reciprocity inherent in relationships (Nichols & Schwarz, 2001, pp. 9, 60). Exploring the structure and process characterising relationships is a key to understanding family life.[74] Family systems theory emphasises interaction and context (Rolland, 1994, p. 11).

A systemic perspective enables one to see more broadly. It recognizes the various subsystems that make up the family system (marital, parent-child, siblings). It also recognizes that what happens outside and around the family has a significant bearing on what occurs inside. For example, the society in which families are situated, defines intellectual disability, provides the labels, establishes social policies and practices, and provides the environment in which families come to terms with intellectual disability (Marsh, 2001, p. 4). A systemic approach focuses on the family, recognizing that the

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[70] "Therefore, for clinicians and researchers alike, *interaction* is at the heart of all systems-oriented biopsychosocial inquiry" (Rolland, 1994, p. 11).

[71] VanKatwyk (2000) describes a system simply as "a complex of interacting elements" (p. 88).

[72] Von Bertalanffy (1968) notes that interdependent parts comprise all living systems, and the interaction of these parts gives rise to characteristics not found in the separate entities.

[73] Therefore, as VanKatwyk (2000) notes, when working with families with children with an intellectual disability, the question might be, "Which part of the family system is best placed to work through the shifts that the family as a whole is being called to make?" Often it is the couple as the executive team that bears the responsibility for negotiating the changes.

[74] "The animating idea of family therapy is that because most human behaviour is interactive, problems can often best be addressed by helping people to change the way they interact" (Nichols & Schwarz, 2001, p. 8).

family interacts with community, cultural, and ecological systems.[75] A number of texts adopt a systemic approach in exploring intellectual disability in the family.[76] Therefore, from a systemic perspective, which recognises the interconnection of the family and the intellectual disability, and from a strategic perspective, which acknowledges that families provide the best platform for intervention, I have decided to explore intellectual disability within the context of the family. It appears to be a reciprocal relationship, where the family and the presence of intellectual disability both define and are defined by the relationship. It was beyond the confines of this research project to explore all the subsystems comprising the family system. I chose to focus on the parents, who are the executive subsystem, responsible for giving shape and direction to family life.

The field of family therapy and family systems theory has evolved over several decades.[77] Nichols & Schwartz (2001, p. 8) identify social constructionism, narrative

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[75] The field of family therapy has moved beyond a simple family-centred perspective to an ecological perspective which sees the family in its broader sociocultural context.

[76] Some of the texts that look at intellectual disability from a family systems perspective include: *The family with a handicapped child,* by Milton Seligman (1983, 1991); *Families with handicapped members,* edited by James Hansen and Evan Imber Coppersmith (1984); *Families of handicapped children,* edited by Rebecca Fewell and Patricia Vadasy (1986); *Families of handicapped persons,* edited by J. Gallagher and P. Vietz (1986); *Families, professionals and exceptionality* by A. Turnbull and H . Turnbull (1986, 1990); *Family interventions throughout chronic illness and disability,* edited by Paul Power, Arthur Dell Orto, and Martha Gibbons (1988); *Chronic illness and disability,* edited by Catherine Chilman, Elam Nunnally, and Fred Cox (1988); *Ordinary families, special children,* edited by Milton Seligman and Rosalyn Darling (1989, 1997); *Families and mental retardation* by Diane Marsh (1992). The numerous chapters and articles include: "Family life cycle: theoretical and empirical implications and future directions for families with mentally retarded members" by A. Turnbull, J. Summers, and M. Brotherson (1986); "Parental adjustment to a disabled child: a family systems perspective" by J. Bernier (1990); "Why families of children with biological deficits require a systems approach" by L. Sloman and M. Konstantareas (1990).

[77] It may be helpful for the reader to have a thumbnail sketch of the evolution of family therapy and family systems theory. It was research on the link between schizophrenia and the family that led to the growth of the new field of family therapy. What researchers concluded from their observation of the link between people with schizophrenia and their families, which was of particular significance, was that certain family dynamics issued from the 'system' rather than shared features of individual family members. Nichols and Schwarz (2001, p. 13) maintain that while the field of family therapy had a long history, it had been born as recently as 1956. John Bowlby, an English psychiatrist working at the Tavistock Clinic in London, experimented with seeing members of the family, rather than simply the identified patient, and so began the shift from individual therapy to what would become family therapy. Nathan Ackerman ran with the idea and introduced family therapy as the primary form of treatment in child guidance clinics in the US. He had suggested seeing all the family members together in 1938. He later recommended examining the family to understand the child rather than vice versa. The nascent field of family therapy later discovered Von Bertalanffy's general systems theory, which gave rise to family systems theory. The 1950s was a decade of high excitement as Bateson, Jackson, and others discovered family therapy and began to formulate family systems theory. There was a time of expansion in the 1960s as different models began to take shape, and the field sought to establish itself in the face of challenge from established and related disciplines.

theory, integrative thinking and sociopolitical awareness as the dominant trends in family therapy during the 1990s. Becvar (1997, p. 211) regards questions of ethics, morality and spirituality as foremost for this decade. In light of these recent developments, this research project has explored the contributions of Faith and Light to families from a systemic, developmental and constructivist (narrative) perspective, with particular reference to the spiritual-vocational dimension of the family system.

A Life Cycle Perspective

There were two predominant movements in early family systems theory. In the West the work of Gregory Bateson and his colleagues (Bateson, Jackson, Haley & Weakland, 1956) centred around the Mental Research Institute at Palo Alto, California, where Bateson (1972), Haley (1976), Satir (1972), and Watzlawick et al. (1974) developed their thought. Their focus was on homeostasis, power, communication and change processes. In the Northeast, dominant theorists such as Ackerman (1938), Bowen (1978), Minuchin (1974), and Whitaker (Napier & Whitaker, 1978) adopted a psychodynamic and developmental approach. The cross-fertilisation of ideas brought together developmental life cycle theory and the tasks associated with each stage, with the concepts of first-order and second-order change.[78] Hill (1971) was the first person to meld family life cycle theory with system theory.

The life cycle is a fundamental metaphor for individual and family psychosocial development (Erikson, 1950, 1959; Levinson, 1978, 1986; Neugarten, 1976). The metaphor suggests that there are normative and successive stages through which the individual, the family and the intellectual disability pass. A life cycle perspective is a view across time (at least three generations) of the emotional system of a family. It

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Competition between various schools of family therapy characterised the 1970s as therapists sought to remain "true disciples" of their particular school. The 1980s brought a maturing of the field with a move to integrate various approaches and develop "metaframeworks." The relativism and constructivism of the 1990s emphasised the diversity of views, and recognised the role that individuals and their culture play in constructing their reality. The feminist critique challenged some of the implicit assumptions in the various models. Current dialogue that is more respectful of the inherent differences between schools has reduced conflict within the field.

[78] I acknowledge my indebtedness to Guilbault (2001, pp. 57-58) for this summary of the field.

portrays how the family organizes itself and how members interact with one another. A life cycle perspective provides a contextual framework from which to understand the impact of intellectual disability on families. The focus of this study was the *launching* phase, which occurs as children leave the family nest. Rolland (1994) identifies three life cycles, which impact on launching: the individual life cycle, the family life cycle, and the intellectual disability life cycle. The individual life cycle highlights the normative tasks and challenges for each member at respective developmental periods. The family life cycle traces the evolution of the family system, as it reconfigures its structure and adjusts its processes at identified stages. The intellectual disability life cycle traces the challenges and responsibilities commensurate with the particular disability and its stage of evolution.

Rolland's Family Systems-Illness Model

Before exploring further each of the cycles it may be helpful to outline Rolland's Family Systems-Illness Model that advances a family-centred collaborative approach to the psychosocial needs of families living with illness or disability.[79] The Model is three-dimensional comprising: (a) illness or disability type, (b) time phase of the illness or disability, (c) family functioning. Its foundation is the interaction over time between the family and the disability. Rolland's Model traces the interaction between the psychosocial aspects of the disability and particular aspects of family functioning: the family's instrumental style; its affective style; the developmental stage of the individual and the family; the family's belief and value system; and its multigenerational history of disability, loss and crisis (1994, p.12)[80] Viewing the illness or disability in the family from a life cycle perspective can give the family a greater sense of empowerment. Rolland advocates that families strive to balance the psychosocial demands of the disability and personal developmental tasks, to secure "independence from" as opposed

[79] "Generally, illness and disability tend to push individual and family developmental processes toward transition and increased cohesion" (Rolland, 1999, p. 500).

[80] Specific components that impact upon family functioning in the presence of intellectual disability include: the meaning the family attributes to the disability; the family's ability to provide in-home care; the family's capacity to communicate, to problem-solve, to reallocate roles, to manage emotional involvement, to access social support and community resources (Rolland 1999, p. 499). Therefore, the family's belief system and the meaning it attributes to the disability is one contributing factor to its overall functioning. It would seem that Faith and Light has a particular contribution to make to family health on this level.

to "subjugation to" the disability.[81] I questioned whether Faith and Light addressed this shift in the relationship between families and intellectual disability.[82]

The Individual Life Cycle

Theorists have proposed various developmental schema to describe human growth. Freud (1916/1935) explored psychosexual evolution; Erikson (1950) set forth eight psychosocial stages; Piaget (1969) considered the moral development of a human being; Kohlberg (1969, 1973) posited cognitive developmental stages in children; Fowler (1981, 1987) has proposed five stages of evolution of religious faith. Typically, members of the family preparing to be launched are dealing with issues around identity, separation, sexuality and vocation. Parents in their middle adulthood preparing to launch offspring are redefining and renegotiating their marriage relationship, their family roles, and their career goals. Levinson (1986) has identified periods of transition and disintegration which intersperse phases of stability and reintegration in the individual life cycle. The launching phase is a period of transition or disintegration in Levinson's terms. Therefore what happens in transition periods may stimulate or arrest development in the ensuing phase. The interaction of issues arising from intellectual disability and from individual life cycles may impact ensuing developmental phases for family members and for the family itself.

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[81] Rolland (1999, p.505) advocates that families "should aim, above all, to deal with the developmental demands of the illness without forcing family members to sacrifice their own or the family's development as a system." He suggests that families examine whose life plans in particular have altered, and to decide when to address developmental goals and tasks which have been delayed because of the illness. He encourages families to explore the resources at their disposal to enable members to pursue their own goals and to provide the requisite care for the family member who is ill or disabled. Often family members need to process and resolve feelings of guilt, over-responsibility and hopelessness .

[82] It could be argued that Faith and Light adopts a contrary stance by placing the intellectual disability at the center of family life. In some families the disability might already occupy center stage at times to the detriment of family and individual development. It may be helpful for some families who are having difficulty accepting the reality of intellectual disability as a family phenomenon to give it increased prominence (*reverse* or *positive* discrimination). The question remains whether it is adaptive as a normative orientation for families with a member with an intellectual disability. It is important to remember that a stance that is functional for one subsystem in the family system (parent-child dyad) might not be functional for another subsystem (sibling subsystem).

The Family Life Cycle

A developmental approach to family dynamics recognises that families evolve, and the changes will impact their structure, functioning and interaction. The family life cycle is a series of developmental stages. At each stage, family members approach the developmental tasks appropriate for that life phase. Theorists have proposed a number of stages ranging from 6 to 24 (Carter & McGoldrick, 1988). Carter and McGoldrick (1980, 1988, 1999a) propose six stages: leaving home, marriage, families with young children, families with adolescents, launching, families in later life.[83] They acknowledge the variation of life cycle tasks for individuals and families, which the wider social and cultural contexts occasion. At the same time they advocate a fluid concept of "predictable stages with appropriate emotional tasks for individuals and family groups, depending on their type of structure, specific cultural background, and current historical era" (1999c, p. 5).

Neugarten (1976) believes that adults carry internalised expectations around the course of their family life cycle, which shape their plans and goals. Stress arises not so much from the crisis which the presence of a family member with an intellectual disability can occasion, but from the upset to the anticipated normal sequence of life events.[84] Olson et al. (1984) found that the most stressful developmental transition was launching. Those events and tasks in the family normally associated with the launching phase include: the marital system reconfiguring itself as a dyad; parents and grown children establishing adult-to-adult relationships; the family system expanding to accommodate in-laws and grandchildren; and family members contending with consequences of ageing and third generation deaths (Carter & McGoldrick, 1999c, p. 2). It was important to bear these tasks in mind, when listening to the reported experiences of parents in the study.

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[83] Olson et al. (1984) and Turnbull, Summers and Brotherson (1986) trace seven stages: couple, childbearing, school age, adolescence, launching, postparental, and aging.

[84] For example, Marsh (1992) includes the following verbatim quotation:

> Now is when I feel it more, when I watch my friend's children going off to proms and getting married. I never got to see her in a communion dress or a prom gown. When [my friend's daughter] got married, I sat there and cried. I'll never have any grandchildren. I feel very, very restricted now. All of our friends can just get up and go (p. 97).

One of the principal differences for parents of offspring with an intellectual disability is that they may find themselves continuing to be involved closely with their offspring's care, long after their contemporaries with nondisabled offspring have launched their daughters and sons.[85] Parents may resent the continuation of primary responsibilities,[86] and young people with disabilities may resent their lack of autonomy. Siblings may feel co-opted into caregiving responsibilities (Seligman & Darling, 1997, p. 13). Turnbull, Summers and Brotherson (1986) have listed the following issues for the family: adapting to the implications of intellectual disability for an adult; decision-making around employment and residential options; addressing intimacy and sexuality issues; accepting continuing emotional and financial responsibility;[87] dealing with guardianship issues; and tackling the restrictions on socialization.[88]

Intellectual Disability as It Impacts on Individual and Family Life Cycles [89]

With the presence of intellectual disability in the family there are certain tasks that remain works-in-progress throughout the family life cycle. Marsh (1992, p. 109) outlines several of them: formulating realistic expectations for each family member; being actively involved in interventions; identifying and accessing social service agencies;

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[85] Marsh (1992) includes the following excerpt:

> I knew she was graduating. We didn't know what we were going to do. This has been the most difficult. I went to the base unit and got her on all the lists. Because we could transport, she was one of the ones who was picked up sooner. It costs me more to take her to work than she's making, but it's giving her a sense of fulfilment (p.101).

[86] "We'll never reach that stage that other people reach when their children leave home, and that's depressing... I wonder what will happen to Brian when he no longer looks like a child" (cited in Darling 1979, p. 184).

[87] Seligman and Darling (1997) include this verbatim account of a father of a child with quadriplegia:

> When our daughter is through the school system, it's highly likely my spouse will have to stop working altogether, and I may try to go to a 32-hour week, due to the wretched support for adults with severe disabilities in this state. Amongst older people we know with severely handicapped children, except those who are wealthy, the norm seems to be care for the child at home as long as possible – often well into the 70s or even 80s (p. 82).

[88] See also Marsh (1992, p. 109). The tasks she lists as specific to the launching/transition phase assuming it occurs in young adulthood include: developing and implementing vocational plans; exploring and deciding upon residential options; working on issues around intimacy and sexuality, including the possibility of marriage and child-raising; developing and maintaining recreational activities; formulating long-range plans.

[89] Rolland (1994, p. 4) notes that family systems theorists have only begun to apply their discipline to physical illness in the last 30 years, trailing other related disciplines such as nursing and social work, whose clinicians have already been publishing on the impact of illness and disability on families for decades.

acquiring coping skills for living with intellectual disability; functioning effectively as a family; finding and creating meaning around intellectual disability; striking a workable balance among all family members; envisioning long-range goals; fostering collaborative relationships with professionals; and tackling sociopolitical issues around intellectual disability.

Intellectual disability radically alters the life cycle of individual members and the family. The meaning and the consequences of the offspring's disability will depend upon the developmental stage of the individual members and the family. Marsh (1992, p. 97) cites Bubolz and Whiren's (1984) term of "energy sink" to refer to the manner in which the presence of a child with an intellectual disability can divert family resources away from the developmental needs of children without a disability. At the launching phase, its presence may impact on the adolescent developmental tasks of nondisabled siblings, as they deal with identity questions, issues around intimacy and sexuality, and separation and autonomy. In addition, the early adulthood issues for nondisabled siblings of finding a partner, commencing a family and establishing a vocation may be affected. The intellectual disability of an offspring inevitably changes the life cycle of the parents. The launching phase is a time when offspring claim more independence, and parents renegotiate roles and commitments, as they make choices about where to reinvest time and energy no longer taken in child-rearing. They may miss the opportunity their midlife peers find to reflect upon and reintegrate their lives, and risk being overburdened with caregiving for their offspring with an intellectual disability and their own aged parents. If parents are older, they may be more concerned about future care-giving for their offspring with an intellectual disability. They may have less time and energy to devote to grandparenthood, to conducting a life review, to dealing with the ageing process and impending death, and to discovering meaning in their lives.

Individuals, families and intellectual disabilities evolve over time, owing to a mix of biological and psychosocial causes, as family members interact with the environment. Different models provide understanding of the stages and the process in the life cycles of individuals, families and the intellectual disability itself. It is important to recall that they

remain theories or models. As such they have been criticised for imposing a linear, orderly development on a process that may be circular and unpredictable, and for their failure to account for the impact of wider social systems within which the particular life cycle is embedded. Bearing this in mind, a lifecycle perspective, particularly as it traces the weaving and melding of the individual, family and disability life cycles provides a useful landscape on which to chart the particular issues or challenges families are facing.

A Competence Perspective

Previous lenses through which families were viewed focused on pathology and dysfunction, leaving families feeling insecure and dependent. Models based on competence recognize family strengths, resources and expertise. They empower families by affirming their adaptive coping skills. Combrinck-Graham (1989; cited in Marsh, 1992, p. 131) traces the development of family systems models albeit in relation to mental illness rather than intellectual disability. In the 1940s it was believed that family pathology caused problems in individual members. In the 1950s and 1960s individual problems were attributed to maladaptive communication in the dysfunctional family. From the 1970s on, the emphasis has shifted to the interactional and cybernetic nature of the family system. The current trend is toward a competence-based view where clinicians seek to collaborate with client families in identifying and promoting resources and resilience.[90]

Froma Walsh's (1996, 1998, 2000) resilience-based approach to work with families is a good example.[91] She maintains that "Families are our most valuable resources in treating

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[90] In a similar vein, Steinglass and Horan (1988; cited by Rolland, 1994, p.5) outline four perspectives albeit in relation to family factors in chronic illness: (a) the family as resource; (b) the psychosomatic family – a deficit model; (c) the impact of the illness on the family; (d) the family's influence on the course of the illness. Rolland's Family Systems-Illness Model emphasizes the interaction between the illness and the family, viewing the family as a resource.

[91] Walsh interacts collaboratively with clients, affirms the personhood and strengths of individual family members and the collective strengths and resources of the family. She promotes healthy family functioning and encourages families to develop support networks to optimize their functioning (Walsh, 1999, p. 320). Her approach affirms the healing and growth potential inherent in families by accessing their strengths and creating further resources for responding to challenges.

serious illnesses" (1999, p. 323).[92] Walsh notes that family relationships can both exacerbate and alleviate the challenges that family members face in having one member with an intellectual disability. She advocates looking closely at the organization of the particular family system, its adaptation patterns and the needs of each member, to determine ways of transfiguring the organizational structure and transforming family relationships. Given the diversity of families with offspring with an intellectual disability, it is important to remain creative and flexible in envisioning the family processes that will promote transformation and growth in family functioning. Faith and Light is a movement that promotes the unique contribution of each member to the community. It recognizes the giftedness of each individual and celebrates the diversity inherent in shared life. Ostensibly it appears to endorse a competence perspective of families. It was important to examine closely the extent to which it promotes the strengths and resources of families when its focus is largely on the *wound* of intellectual disability and the suffering associated with it.

The Launching Phase

A life cycle perspective holds that the launching phase in the family life cycle involves second-order change and a number of associated tasks. There will be differences on both levels between families with offspring with an intellectual disability and conventional families (see Table 1). While Rolland (1994) does not expand on launching, he does identify "transition" phases in the family life cycle.[93]

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[92] As well as giving adequate consideration to the developmental needs of each family member, Walsh (1999) suggests that therapists look beyond the immediate family to identify potentially significant relationships with members of the extended family: "reification of the nuclear family model has pushed the extended family to the margins, much to the detriment of us all" (p. 323).

[93] In describing "transitions," Rolland extends Levinson's (1978) developmental life structure model for adult males, which differentiates between stable or life structure-building/maintaining phases and transitional or life structure-changing periods, each lasting from five to seven years. Rolland applies this model by analogy to the evolution of families. He argues that transitional phases can be times of vulnerability because of the need for re-evaluation of family priorities and structure accompanying new developmental tasks (1994, pp. 104-105). "They are often characterised by upheaval, rethinking of previous commitments, and openness to change" (1994, p. 115). It can be a time when commitments are re-examined, and when family rules of loyalty through self-sacrifice and caregiving may prevail. Some family members may avoid decisions regarding their own future by focussing excessively on the needs of the member with an intellectual disability, increasing the likelihood of family dysfunction.

Table 1

Comparison of Dynamics and Functioning in Two Family Types

Themes	Families with offspring with an intellectual disability	Families with nondisabled offspring
Occurrence of Launching	Launching may or may not occur	Launching generally occurs
Holding on/Letting go Dialectic	Preponderance of centripetal forces over centrifugal forces. Holding on may dominate in holding on/letting go dialectic	Preponderance of centrifugal forces over centripetal forces. Letting go dominates in holding on/letting go dialectic
Separation	May be ambiguous with high degree of continuing contact	Often clearly defined with a marked change in degree and nature of contact
Frequency	May be one in a series of transitions parents have already negotiated with offspring: initial diagnosis; initial education placement; leaving school (Simeonsson & Simeonsson, 1981; cited in Marsh, 1992, p. 79, 102-3)	Often qualitatively different to any other life cycle transition parents have negotiated with offspring, demarcated by graduation, economic self-sufficiency or marriage (Turnbull et al., 1986)
Implications for Caregiving	Caregiving and involvement with offspring may increase	Caregiving and involvement with offspring generally decreases
Responsibility	Parents may see parental vocation as perpetual	Parents recognise that while some responsibilities continue they now have more freedom
Parental Freedom	Parents may not have extra time to devote to their relationship nor to their own identity/vocational questions	Parents have time and energy to renegotiate marital system as a dyad and deal with own identity/vocational questions
Continuing Relationship	Parents may continue to see their offspring as dependent "children"	Parents and grown offspring develop adult-to-adult relationships
Expanding Family Unit	Parents may experience ongoing grief around relinquishing dreams of offspring's marriage and grandchildren	Parents revise family unit to accommodate in-laws and grandchildren
Aging	Aging parents may experience ambivalence or anxiety over their continuing ability to care for offspring along with recognition of the companionship and sense of purpose they derive from caring for offspring (Turnbull et al. 1986)	Parents come to terms with their own aging and with death of parents (grandparents)
Family Life Cycle	Parents may be dealing with two family life cycles of their offspring with and without an intellectual disability	Parents generally are experiencing one family life cycle

The transition to early adulthood is a significant junction for all members of the family.[94] He suggests that parents retain a sense of empowerment in times of transition by: (a) acknowledging losses they are experiencing, and those which they may encounter; (b) engendering hope; and (c) instilling flexibility into family life cycle planning that preserves and modifies major goals.

Whether or not offspring with an intellectual disability leave their family home, some of the tasks facing parents and other caregivers include: (a) adapting to the adult implications of intellectual disability: (b) making decisions regarding living, work and recreational matters; (c) responding to issues surrounding sexuality, including dating; (d) accepting continuing responsibility and the corresponding financial implications; (e) planning for guardianship; and (f) dealing with reduced opportunities for social contact for offspring. If offspring leave the family home, parents face further tasks beyond those of their counterparts with nondisabled children: (a) interacting with various agencies, service providers, and caregivers; (b) dealing with offspring's issues around possible relationships and childbearing; and (c) ensuring long-term financial security for offspring. If parents are aged when their offspring depart, their tasks may include (a) planning for continuing care and supervision after death, (b) coming to terms with their own personal issues around residential placement, and (c) delegating their parental responsibilities to others (Marsh, 1992, pp. 101-102).[95]

Rolland's Model emphasises the impact of the conflation of life cycles on family structure and process. It is important to consider the phase in the development of the intellectual disability,[96] as well as the stage of individual development of all family

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[94] Often there is a powerful resurgence of issues related to anticipatory loss and unresolved problems relating to blame, shame and guilt. Limits, unrealistic hopes, and issues of permanent dependence come to the fore in the context of major developmental tasks of the period, which include: emancipation from parental controls, leaving home, and setting up a first independent life structure in which the "centre of gravity" shifts from the family of origin to a new home. It is noteworthy that all developmental transitions involve beginnings, endings and losses, often confronting members with their own limit and mortality (Levinson, 1978; cited in Rolland, 1994, p. 216).

[95] For other discussions of tasks facing families of young adults with an intellectual disability, see Brotherson, Backus, Summers, and Turnbull (1986), and Seligman and Darling (1997, p. 80).

[96] Rolland (1994, p.50) differentiates between the time phases of an illness or disability: crisis, chronic and terminal. Transitions between each of these phases in the life cycle of the intellectual disability require re-

members, as the family approaches the launching phase for the member with an intellectual disability. Intellectual disability in one member can have a significant influence on the developmental goals of another member. Generally speaking, intellectual disability increases family cohesion. At times normative enmeshment may be adaptive as the family strengthens its personal and generational bonds in adjusting to the presence of intellectual disability. However at the launching phase when issues of autonomy come to the fore, they are likely to challenge the vulnerabilities of enmeshed families (1994, p. 50).

Guilt is a phenomenon well-attested to at this phase. Mothers may blame themselves for the condition, and wonder whether they are doing "the right thing" in placing their offspring outside the family home. Parents may experience a sense of failure from not having protected their offspring with an intellectual disability from suffering. Both siblings and parents may suffer from *wellness guilt* and subvert or abandon their own life ambitions. There can be deep ambivalence surrounding this stage for family members. Offspring with an intellectual disability may want to emulate peers; parents may want to protect their offspring from disappointment. It is important that offspring with an intellectual disability have the opportunity to develop their own relatedness and autonomy[97] so far as is possible, which might necessitate a realignment of the former parent-child relationship. Parents may experience greater challenges in redefining parent-child relationships as adult-to-adult relationships. The adult offspring may need help in resolving long-standing emotional issues with parents, and the parents have a crucial role to play in this (Blacker, 1999, p. 300).

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evaluation of a family's mechanisms for coping and adaptation. A discernible shift in the disability life cycle might enhance the stress associated with individual and family transitions. For example, there may be conflict between the progressive course of an intellectual disability, requiring more care, and a sibling's transition to early adulthood, and a family's transition from the raising-adolescents stage to the launching-young-adults stage (p. 116). In this study, all of the offspring involved were settled in the chronic phase of the intellectual disability life cycle.

[97] Fulmer (1999) observes that young adults experience pressure to individuate or separate from the influences of family and society. He believes that some of this pressure finds its source in autonomy-based theories of development as identified by Gilligan (1982). He advocates redressing the balance by emphasizing a continuing need for relatedness during this developmental phase.

There are numerous issues identified in the literature for parents of offspring with an intellectual disability at the launching phase. This study explored the reported experiences of parents as their offspring reached adulthood, and their perception of the role of Faith and Light as they negotiated the challenges.

Stress and Coping

The Family Adjustment and Adaptation Response (FAAR) model blends family stress theory and family systems theory (McCubbin & Patterson, 1983; Patterson, 1989; cited in Rolland, 1994, p. 6).[98] It holds that families undergoing a major stressor such as intellectual disability respond with their resources and coping skills.[99] The focus is on the *process* of responding to stressors before the *content* of the stressors themselves. A crisis arises when the demands of a situation exceed the capacity to respond adaptively. Equilibrium returns when the family acquires further resources or coping skills, the stressor diminishes or the family views the situation differently. It is the *resources* a family has, and how the family *interprets* the stress that are the two pivotal factors in determining how a family copes with stress (Hill, 1949). Therefore, one critical factor in the family's adaptation is the meaning it attaches to its capabilities and to the stressor. The pattern of adjustment/crisis/adaptation repeats through the family's normative life cycle transitions and through the disability life cycle. It seems that Faith and Light as a community could be a resource to families, as well as offering alternative interpretations of the stressors they encounter.

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[98] McCubbin and Patterson's (1983) "Double ABCX model" is an adaptation of Hill's (1949) ground-breaking ABCX Model. The stressor (a) interacts with existing resources (b) and with the family's perception (c) to produce the potential crisis. Where the crisis is not resolved satisfactorily there can be a "pile up" which serves as another stressor (aA). Existing and new resources (bB) and the family's initial definition of the stressor and their redefinition of it in light of new experiences (cC) interact with the "pile up" (aA) to generate the family response, ranging from bonadaptive to maladaptive.

[99] Some definitions may be helpful. Stress is a "state which arises from an actual or perceived imbalance between the demands of life and the family's capability of meeting those demands." *Distress* is a negative family assessment of the stress (a threat to the family); *eustress* is a positive family assessment of the stress (a challenge to the family). A crisis is "a state which demands the family change its basic structure of being and doing in response to the stress." A family crisis calls for second order change. Interestingly Hill (1949) found that often a family's level of organization will be higher after a crisis than before it. The family discovers more of its own resources in the crisis. I am indebted to Prof. P. VanKatwyk for these definitions that he used in unpublished lecture notes dated November 14 2000.

Evidence suggests that stress is a given in family life.[100] Carter and McGoldrick (1999, pp. 5-6) differentiate between the horizontal and vertical flow of stress in a family's life cycle. The horizontal stressors include the predictable developmental transitions that a family negotiates in its life cycle and unpredictable events such as untimely death, chronic illness, accident or unemployment. The vertical stressors impact the family at a particular moment in time, and include sociocultural factors, such as prevailing societal beliefs and social hierarchies, as well as family emotional patterns, myths, secrets and legacies, congenital disabilities and personality traits. The meaning which the family assigns to the stressors depends on the "historical consciousness" or "traditions"[101] of the family within which the members construct their interpretation. Therefore the family's *script* or *mythology* influences significantly how the family creates its reality and how it interprets the meaning of the stressor.

Family stress often increases at transition points in the family's developmental life where parents may experience renewed anxiety and loss. In times of life cycle transition, families often need to reconfigure themselves as they find different ways of striking the balance between separateness and togetherness, or expansion and contraction in family life. Therefore in families with offspring with an intellectual disability at the launching phase it is important to consider not only the normative and non-normative stressors (the horizontal axis), [102] but also interactional patterns, family themes and legacies which impact across generations (the vertical axis). The meanings, which families attach to stressors at the launching phase occur across a number of levels: individual, family, social, religious, and cultural. "Although all normative change is to some degree stressful, when the horizontal (developmental) stress intersects with a vertical (transgenerational)

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[100] Not all stress is out of the ordinary. Figley (1983; cited in Marsh, 1992, p. 76) identifies 11 characteristics that contribute to stress being abnormal rather than normal: (a) absence of, or minimal time to prepare; (b) minimal prior experience; (c) minimal guidance; (d) not widely experienced; (e) extended time in crisis; (f) lack of control and feelings of powerlessness; (g) experience of loss; (h) disruption and distraction; (i) high degree of threat; (j) significant emotional impact; (k) associated medical issues. While news of the diagnosis of intellectual disability, might constitute abnormal stress on these criteria, it is questionable whether the launching or transition period would constitute abnormal stress.

[101] Paul Tillich proposed that the interpretation of events occurs within the context of "historical consciousness" or "tradition." The "tradition" consists of those significant events in the life of a group which the group chooses to recall. They contribute to the group's self-identity.

[102] Restricted work and living options when the child finishes school may occasion significant stress for parents (Seligman & Darling, 1997, p. 28).

stress, there tends to be a quantum leap in anxiety in the system" (Carter, 1978; cited in Carter & McGoldrick, 1999, p. 6). Developmental tasks not undertaken at the appropriate time or unresolved emotional issues may impact upon future transition points.

How the various systems of immediate family, extended family, community and society interact with each other has a significant bearing on how the family negotiates the launching phase. Carter and McGoldrick (1999c, p.20) emphasise that some of the issues that families encounter as their offspring with an intellectual disability attain adulthood find their roots not in intrapsychic or interpersonal dynamics within the family but in the social system of which the family forms a part. The historical and sociocultural context in which the family lives impacts upon the stress inherited from past generations and that encountered in the developmental family life cycle. What is normative for one family in one context around autonomy of offspring, may not be normative for a family in a different context (Seligman & Darling, 1997, p. 81). At the beginning of the twenty-first century in North America it is important to assess the anxiety generated by being an "imperfect family" or a family with an "imperfect" member in a sociocultural context, which places such emphasis upon "perfection." Where the same sociocultural context demands economic efficiency, families with members who will never contribute financially to that society and will likely require financial assistance from that society, face increased stress from their surrounding context. Similarly, it is important to recognize that *ability* is not simply a difference. It is a hierarchical distinction with preferential treatment accorded to those who have more. It may be that societal bias around *ability* contributes to the conflict that family members attribute to one another. Societal inequity translates readily to family disharmony.

The issue of stress raises that of coping behaviours. Beckman and Porkorni (1988; cited in Seligman & Darling, 1997, p. 22) have shown that social support reduces family stress. Seligman and Darling (1997) promote both formal and informal social support as a means of countering family stress, enhancing adaptive personal and family functioning and maintaining a sense of normalcy (pp. 24, 116). Ostensibly it seems that Faith and Light can fulfil this role. Seligman (1993) observes that self-help groups can offer a place

for family members to express feelings, to share information, to provide assistance and to advocate. Faith and Light, while not a self-help group per se, probably provides members with the opportunity to share intimately and to help one another. Zucman (1982; cited in Seligman & Darling, p. 116) draws attention to the phenomenon of social isolation amongst families with children with a disability.[103] It can intensify as the children grow older if families continue to entertain unrealistic hopes for their offspring's future. Organisations like Faith and Light can provide a forum for connecting families with other families in similar situations, and offer a reality check on the nature and permanence of the disabilities.

Grief

Empirical studies and anecdotal reports testify to the grief that parents of offspring with an intellectual disability experience.[104] Some researchers subscribe to Kubler-Ross's (1969) stage-theory of grief, while others are more circumspect, particularly as it applies to parents of children with a disability (Blacher, 1984; Mary, 1990). It is likely parents will continue to mourn throughout the life of their child, and that their emotional responses may be more pronounced at developmental nodal points in the life of their offspring, such as the launching phase. While there is extensive literature on the initial and continuing grief experience of parents, it remains difficult to validate empirically the stages that parents pass through. Hornby (1994) observes that some families might negotiate the entire grief process reasonably quickly; other families might experience different reactions simultaneously. Olshansky (1962) coined the term "chronic sorrow" to describe the psychological responses to the disability, which parents experience throughout their lives. Factors such as the level of intellectual disability, the temperament

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[103] The presence of intellectual disability can segregate a family. "The diagnosis of mental retardation often seems to serve as a familial membrane that quarantines the family from mainstream society" (Marsh, 1992). Explanations include: family exhaustion, assumed stigma by family members, social isolation through intolerance, support needs of the extended family, and the particular needs of children with disabilities (Marsh, 1992; Seligman & Darling, 1997, p. 24).

[104] For example, Rando (1986) has shown that the grief of parents increases stress in a marriage and can precipitate divorce. Some pertinent questions for exploring parental grief include: At what stage in the couple life journey is disability thrusting its presence on to the family stage? What are the grieving styles of the respective parents? How do couples in the formative stages of their shared growth cope with the inevitable reality of the absence through grief of the other as partner?

of the parent, ethnicity, religious affiliation and socioeconomic status influence the degree of sorrow experienced. Olshanky suggests this is a normal response to parenting a child with a disability, and does not indicate a lack of competence or care as a parent.[105]

Families may face many *deaths* as they respond to their member with an intellectual disability rather than just one. Starting school, formation of peer groups in adolesence, commencing work, and finding a partner are stages that may occasion further senses of loss. The lack of ritual to mark the various losses or deaths may render the losses more difficult to identify and acknowledge. Pauline Boss (1999, pp. 8-9) uses the term "ambiguous loss" to recognise that a person can be perceived as being physically present, but psychologically absent (and vice versa). She draws a clear distinction between ambiguous loss and ordinary loss. "Ambiguous loss is the most stressful loss people can face" (p. 20). It may be that the phenomenon of ambiguous loss captures the sense of sorrow that parents have described.[106] This loss and other losses may continue to be operative as their offspring with an intellectual disability attain adulthood, and families enter the launching phase. Typically parents grieve the loss of the "ideal child," in Bagarozzi and Anderson's terms (1989), the bearer of the couple's dreams of rewriting their own personal histories. There may yet remain elements of this conjugal myth at the launching phase, bringing a renewed sense of loss as the offspring enter adulthood. Another of the losses that parents may encounter at launching is their loss of control to protect their offspring with an intellectual disability from suffering. Rolland (1994) argues that parents need to allow their offspring to take responsibility for their own suffering, as they find their place in society. At the same time families work to redefine their sense of mastery in identifying those areas over which they still exert some control, such as information-gathering and care-giving (Rolland, 1994, pp. 211, 217). While there

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[105] See Marsh (1992, pp. 121-123) for a useful discussion of "chronic sorrow."

[106] It seems that the concept of ambiguous loss may be helpful for these parents. Boss (1999) bases her findings on four working assumptions: (a) Change or threat of change in family organization can cause stress, and adaptation to change may be dysfunctional; (b) families can recover by learning how to manage stress; (c) sharing knowledge empowers families to cope with loss more adaptively; (d) symptoms of unresolved grief are similar to PTSD. She describes her approach in working with families dealing with ambiguous loss:

> My approach centers on encouraging couples and families to talk together, sharing information as well as their perceptions and feelings, and eventually come to a consensus on how to celebrate the part of their loved one that is still present and mourn the part that is lost (p. 24).

may be grief issues for parents as their offspring with an intellectual disability leave home, there may be stress if they remain in the family home, owing to frustrated expectations of parents and the increased complexity of the family household with adult offspring present. Blacker (1999, p. 299) notes that the essential element in parents' response is their *interpretation* of the continuing presence of their adult offspring.[107]

McGoldrick and Walsh (1999) maintain that a family's ability to accept loss is "at the heart of all strengths in healthy family functioning" (p. 185). Healthy families are able to get perspective on the loss and integrate the experience into their continuing life. As the family moves through the life cycle, different layers of meaning associated with the loss emerge, and interact with other losses the family experiences. The grief process is complex and varies widely according to individual and family coping styles. Nonetheless McGoldrick and Walsh (1999, p. 186) identify two tasks fundamental to the family's adaptive processing of a loss.[108] First, each family member needs to confront the reality of the loss in her or his own way. Adequate information and clear communication around the facts and circumstances of the loss facilitate this task. Second, the family needs to reorganize itself in some way, realigning relationships and redistributing family roles.[109] Cohesion and flexibility are assets in performing this task. Loss often requires that family members draw closer together in support of one another. Losses in whatever form they are experienced tend to have a life of their own and be experienced repeatedly. The process of grieving may last longer than family members expect and take different forms depending on the phase of life cycle the family finds itself in. Walsh and McGoldrick (1988) identify factors that influence the impact of the loss in the family: (a) the timing of

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[107] Class and ethnicity also play a significant role in the parents' interpretation of their adult offspring's presence. The expectations of upper-middle class white parents may differ markedly from those of underprivileged African American parents. In the latter case parents may simply assume that they will parent their grandchildren in their own home (Blacker, 1999, p. 299).

[108] Worden (1991) advocates a task-oriented approach to the grief process. He believes there are four essential tasks which one needs to accomplish in order to complete the mourning process: accepting the reality of the loss; working through to the pain of grief; adjusting to an environment in which the deceased is missing; emotionally relocating the deceased, and moving on with life (pp. 10-19). He prefers "tasks" to "stages" (Kubler-Ross, 1969) or "phases" (e.g. Bowlby, 1969/1982) as it implies activity rather than mere passivity on the mourner's part. "Tasks" are more consonant with Freud's concept of grief (Worden, 1991, p. 35).

[109] Family organization is a key to family grief patterns. Enmeshed families often experience difficulty in coming to terms with the death of a member (Kerr & Bowen, 1988, pp. 97-107).

the loss; (b) the coincidence of the loss with other significant life cycle transitions; (c) the history of loss, and unresolved grief; (d) the degree of disability. It is family members themselves who are the greatest resource for one another in promoting recovery and healing. The loss can strengthen relationships and develop resources to cope with future challenges.

This paper emphasizes the relational context of intellectual disability. Intellectual disability occurs in a family, situated in the wider context of a society and a culture. Losses which members experience at the launching phase occasioned by the presence of intellectual disability are *family phenomena.* Shapiro (1994), in her family-centred work on grief, advances the concept of "relocating," rather than relinquishing one's ties to a deceased beloved.[110] Relocating means finding different ways of maintaining a continuing relationship with the deceased that reflect the reality of his or her physical absence, and that do not impede life in the present. In a similar way, family members may need to *redefine* (rather than relocate) their relationships with members with an intellectual disability as they approach adulthood. Where loss is experienced during the launching phase, family members may need to work at redefining their relationships to accommodate the new family configuration.

VanKatwyk (2003) proposes several concepts around grief in a family from a systemic and constructivist perspective, which relate to grief families may experience at the launching phase. First, while intellectual disability is an extraordinary phenomenon, it occurs in the course of the growth and development of family. As such its presence, while posing significant challenges and involving pain and grief, can also provide an opportunity to develop and utilize resources, of which families might not otherwise have

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[110] The loss of dreams that parents had for their child with an intellectual disability is an important phenomenon in the grieving process. Firestein (1989; cited in Marsh, 1992, p. 123) identifies particular dreams that might be dashed: dreams of a healthy baby; of the joy of friends and extended family; of a satisfaction at the conclusion to the pregnancy; of pride at achievement of developmental milestones; of encouragement at the infant's developing autonomy; of the release from tasks of child-rearing. It might be that the concept of relocation or *redefinition* is helpful. Is there a way in which the dreams of parents can be redefined rather than relinquished, or do they simply need to die? Are the dreams relocated on to other siblings without a disability? How do parents redefine dreams for their child with an intellectual disability without relinquishing them? Is there a way of incorporating their dreams into the continuing life of the family?

been aware. Second, the response of members to the presence of intellectual disability in the family and the family's resolution of issues at the launching phase is unique and personal.[111] Members will each have their own emotional responses and will have their own ways of adapting their places and roles in the family in response to the changes occasioned by launching.

Third, the process of coming to terms with disability in the family is developmental and systemic rather than a linear progression. The process occurs at a number of different organizational levels in the family: the biophysical, the psychosocial, and the spiritual-vocational.[112] When the member with an intellectual disability reaches adulthood, the issues present at launching and the loss members experience, will impact the family's identity at each of these levels.[113]

Fourth, the process of dealing with loss is active[114] and family members need to engage in it and with it. Family members need to engage actively with the challenges associated with the launching phase. This may require change in routines and in life direction. It may demand physical energy, and there may be intense emotion to experience and to

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[111] McGoldrick (1999, p. 119) points to the different coping skills women and men have in dealing with loss. Fathers, in coming to terms with the birth of a child with an intellectual disability, are more likely to distance themselves through investing in work, and may be uncomfortable with their partners' overt emotional responses. Mothers may experience this unavailability as abandonment and therefore a double loss. Women may present with depression. It is important that all family members can grieve in their own ways and support one another in their respective grieving styles. Role flexibility facilitates the process of adapting to the loss as a family. Men may need encouragement to enter into the social and emotional dimensions of grieving.

[112] The biophysical level, as it names suggests, describes the physical context of home and the connection of family members to it at a sensual level: the smells, the tastes, the sounds, the rituals. The psychosocial dimension sets out the role definitions of family members, and their place within the family. The spiritual-vocational dimension speaks to the way in which members understand and see one another. Families need to be secure in their own identity to recognize that members are part of the family and that they have identity and function beyond the family. VanKatwyk (2003) believes that "the spiritual vocation of the family is to transcend its own identity as a family clan and confirm the integrity and the calling of its individual members" (p.109).

[113] At different phases of the process, different dimensions may be in ascendancy. In the initial stages of diagnosis family members may experience the presence of disability in the family in physical ways. For example, members may be shocked, angry, confused, or devastated. At another stage, psychosocial phenomena may dominate, where members may find themselves reworking their sense of who they are, and where they fit in, in the family picture and the world. A third stage involves creating a revised story around family life and one's own journey to accommodate the presence of disability in the family.

[114] Worden (1991) refers to the "tasks" of grieving. See fn. 108.

express. Changes will likely occur in relationships, and there is often the work of finding new meaning in life, and in one's own identity (Attig, 1996, p. 55).

Fifth, the process of dealing with any losses experienced around the launching phase is cognitive as well as emotional. From a constructivist perspective, the task of resituating oneself in a world that no longer looks the same is fundamental to the process. Issues encountered at the launching phase may alter the way in which members understand people, relationships, the world and God's presence and activity in the world. In some ways family members may need to relearn themselves and relearn the world, as they create and discover new meanings and new realities for themselves.[115] Sixth, even at launching, family members may need to remind themselves that the process is about accepting the disability, and that it is not about curing or resolving it. Family members learn to live with the presence of intellectual disability in their family. An offspring's leaving the family home does not remove the presence of intellectual disability from the family. Successful adaptation in a family accommodates the wound of disability rather than removing it.

It appears that the issues encountered at the launching phase may occasion grief in parents. It is a process that families as a whole experience, which invites the discovery and creation of new meaning. A systemic and constructivist perspective yields insight into what families might experience. It would seem that Faith and Light as a community group is well-placed to facilitate the grieving process for family members by providing opportunities to share experiences with others. It may be that the movement could offer families more than it presently does through formation and education in this area. Faith and Light by its nature does promote different scripts for families through its narratives and its corporate life that might help families to resituate themselves in a world that may be quite different to that which they had envisaged for themselves.

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[115] Niemeyer (1997) describes emotions from a constructivist perspective as the "signals of the state of our meaning-making efforts" (p. 172). They are "dimensions of transition" that describe one's location in the process of reconstructing one's perspective.

Family Belief System

Family systems theory has held different views over time as to what is most important in human experience, and therefore where the focus lies in directing therapeutic intervention. Emphasis on family interaction (time) and on family structure (space) has given way to recent emphasis on the stories by which families make sense of the world around them (VanKatwyk, 2000, p.96). Constructivism and social construction theory maintain that through people's interaction and communication with one another meaning is created rather than discovered (Anderson & Goolishian, 1988; Gergen, 1985; von Glaserfeld, 1987; Hoffman, 1990; Watzlawick, 1984; White & Epston, 1990). Together people construct narratives that represent and create meanings that interpret the world and the place people occupy in it. Narratives incorporate belief systems that provide a means of organising and making coherent the deluge of stimuli people receive. Beliefs are operative at the personal level through to the level of entire cultures. Reiss' (1981) research shows that families as a unit develop their own belief systems or paradigms through which they interpret the world.[116] Family systems generate their own beliefs around health, illness and disability in their shared construction of reality which all family members inherit (Ransom, Fisher & Terry, 1992; Rolland, 1987b, 1993, 1994, 1998, 1999; Wright, Watson, & Bell, 1996).

It is important to identify family beliefs that influence family narratives and coping strategies operative at the launching phase (Rolland, 1994, pp. 463-467).[117] Rolland

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[116] Family mythology is a positive belief system that gives coherence and direction to life. *Gestalts* are those configurations that people use to process all the information they receive, and to give coherence to the world in which they live. What is experienced is arranged in narrative form or *stories*. People constantly edit what they experience, and they see or attend to that which reinforces the story by which they live. In this way people both create and are created by the stories they live.

[117] Rolland (1994, p. 133) advocates that clinicians map the family's belief system that shapes its narratives around disability and its coping strategies. The contours that define the belief system map of a family with a member with an intellectual disability include: (a) normality; (b) the mind-body relationship; (c) control and mastery; (d) optimism/pessimism; (e) rules of communication; (f) meanings that the family, ethnic group, religion, or surrounding culture attach to the disability; (g) presumed cause(s) of the disability and factors influencing its development; (h) multigenerational legacies, myths, and patterns that shape the family's response to disability; (i) ethnic, cultural and gender-related expectations around roles and behaviours; (j) family rituals; (k) anticipated pivotal moments in the individual, family and disability life cycles requiring a shift in beliefs around health and disability. Clinicians need to evaluate the fit of the

argues that there are core beliefs that underpin family functioning, and upon which specific beliefs around health and disability are built.[118] He identifies three issues that are fundamental to family beliefs around intellectual disability: (a) the family definition of "normality" and the value it places on conformity to society's definition of normal; (b) the family understanding of locus of control in intellectual disability – internal, external by chance, external by powerful others (Levenson 1973, 1974, 1975; cited in Rolland, 1994, p. 138);[119] (c) the causes the family attributes to the disability.[120] The meaning a family generates around these issues will have a significant bearing on how it responds to the challenges generated as their offspring with an intellectual disability attains launching age. Rolland (1994, p. 127) refers to the work involved in creating an empowering narrative around disability. It is a task that families need to take up, as belief systems have a critical influence on how a family adapts to intellectual disability, and deals with

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family beliefs around disability with beliefs held in other subsystems of the family, and with beliefs held in the health-care system and in the surrounding culture.

[118] Kluckhorn (1960; cited by Rolland, 1994, pp. 131-133) is an anthropologist who identifies five universal "dilemmas" of humankind, out of which various orientations arise: (a) human nature as good, evil, or mixed/neutral and as static or dynamic; (b) family focus in time on the past, present or future; (c) human existence as predominantly being, being-in-becoming or doing; (d) human/nature relationship as one of subordination, harmony or domination; (e) human/human relationship as lineal (hierarchical/cross-generational), collective and individualistic. It may be worthwhile to reflect on how Faith and Light might influence each of the areas that Kluckhorn (1960) identifies. First, as regards human nature, Faith and Light would hold that everyone is made in the image of God. Each person therefore is a being of infinite worth and dignity entitled to profound respect. At the same time all humanity shares in a brokenness, woundedness or fragility, which is a uniting bond. Second, Faith and Light advocates presence to one another through attentiveness and small acts of kindness. It implies a living in the here-and-now. Third, Faith and Light encourages being with others rather than doing things for others. In this sense it distinguishes between communion (being with) and generosity (doing for). It recognises that compassion means acting to alleviating suffering; it also acknowledges that at times no further action can alleviate the suffering, and one is called to presence rather than activity in the suffering. Fourth, the spirituality of Faith and Light remains fundamentally anthropocentric, and does not address specifically environmental issues. Nonetheless the movement appears to endorse humankind's responsibility for just and equitable stewardship of the created order (cf. Ps. 24.1, "The earth is the Lord's and all that is in it, the world, and those who live in it"). Finally, human/human relationships is probably the area to which Faith and Light speaks most directly. Relationships are to be marked by profound respect for one another, by presence to one another and by acceptance of each other's vulnerability and woundedness, by a recognition of one another's giftedness and a celebration of differences, and by tenderness, humility and gentleness.

[119] An internal locus of control suggests that the family can influence the outcome of a situation; an external locus of control implies either that the family sees powerful others as determining a course of action, or that occurrences happen by chance or according to fate. Over the course of the disability there is a varying relationship between a family's beliefs around mastery and what the disability itself dictates in a given situation (Rolland, 1994, p.140).

[120] "Optimal family narratives respect the limits of scientific knowledge, affirm basic competency, and promote the flexible use of multiple biological and psychosocial healing strategies" (Rolland, 1993, p. 466).

developmental nodal points in its life, such as launching.[121] The narratives around intellectual disability that Faith and Light live have potential to influence the belief systems of families.

Ethnicity, race, and religion are strong determinants of family beliefs around disability, and of the resulting actions taken at transition phases such as launching. There may be radically different interpretations of intellectual disability and of consequent actions for family members, which calls for tolerance and flexibility. It is those families that can balance a need for consensus with respect for divergent views that tend to fare best.[122] Differences in belief amongst family members often emerge at transition points such as leaving home (Rolland, 1994, p.164). In addition, intellectual disability assumes different meanings at new developmental stages, which vary according to the type of disability. Reinterpretation is an essential part of working with families experiencing difficulties in living with intellectual disability.[123] As families generate new meanings and in turn discover and create transformed personal and family realities, they change.[124] The family is transformed because its members situate themselves in and to the world differently with a reorientation of their core beliefs. "A basic task for families is to create a meaning for a health condition that preserves its sense of competence and mastery" (Rolland, 1994, p. 9). It is in this reinterpretation or reorientation that Faith and Light has a potential role to play.

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[121] "Belief systems are a tremendous force in illness. When misused or disregarded, they can wreak havoc on relationships and block healing. When utilized sensitively, they empower all relationships and provide a foundation for biological and psychosocial healing" (Rolland, 1994, p. 131).

[122] Families with flexible belief systems are more likely to exhibit adaptive family functioning (Rolland, 1993, p. 467).

[123] VanKatwyk (2000, p. 102) rightly observes that narratives arise out of a relational context, and blend word and action. The presence of disability in the family is a radical intrusion upon its life and the stories it lives by. Reconciling itself to the presence of disability entails facing the loss and rewriting the family narratives.

[124] Family systems theory identifies three levels of change. First-order change describes change that leaves the structure of the family system intact. Second-order change alters the structure of the system itself. Third-order change, the most radical, is a shift in orientation or perspective (e.g. VanKatwyk, 2003, pp. 102-103).

Summary

In this section I have outlined some features of a theoretical context drawing on research and theoretical literature in family systems theory, the individual, family and intellectual disability life cycles, stress and grief theory, and family belief system theory within which to locate parents' experiences. The phenomenon of intellectual disability occurs in a relational context and there will be implications throughout the family system. The metaphor of a life cycle is well supported in developmental psychosocial literature. Rolland posits that in participant families there will be a conflation of the life cycles of individuals, the family and intellectual disability itself. There will be particular phenomena associated with the launching phase in families with offspring with an intellectual disability. A competence perspective focuses on the strengths and resources of families. Stress and coping theory identifies horizontal and vertical stressors which can interact to exacerbate the stress of parents. It highlights the role of resources and interpretation in adaptive coping patterns. There are aspects of grief theory from a systemic and constructivist perspective that assist with understanding the lived reality of parents. Finally, the literature underscores the influence of a family's belief system on its response to intellectual disability. It seems that for parents dealing with launching issues, Faith and Light could operate both as a social and spiritual resource to families, and as purveyor of liberating narratives around intellectual disability, loss, relationships and God.

In the first three chapters I have set the stage by laying out a theological pastoral care and counselling, the nature and the activity of Faith and Light, and selected social science theory relevant to families of offspring with an intellectual disability and the launching phase. In the following chapter, I outline the qualitative research method used in this project to explore the experiential world of the member parents, and the role of Faith and Light as a provider of pastoral care to its members.

Chapter Five

METHODOLOGY

Rationale for Qualitative Methodology

Myers (1996) argues for congruence between research methodology and the research subject. It is important that the methodology chosen "fits" that which is being researched, rather than the subject of research being constrained to fit in with a predetermined research method.[125] Traditionally, empirical quantitative methodologies have dominated the social science research field. Quantitative research involves a statistical analysis of operationalised variables in numerical form (Sprenkle & Moon, 1996, p. 9). It is built upon the measurement of amount, intensity or frequency (Denzin & Lincoln, 1994b). In qualitative research one begins with a question to be explored rather than a hypothesis to be tested. The term *qualitative* describes how data is collected and analysed. Broadly speaking, qualitative methodology involves an inductive analysis on verbal or observational data. There are a multitude of qualitative techniques.[126]

What makes a qualitative approach a good fit for this enquiry? Essentially, qualitative methodology is better suited to research concerned with process and meaning. It is compatible with systems thinking. It allows for insights around process to emerge, and it substantiates research that is "discovery-oriented" (Sprenkle & Moon, 1996, p. 5). The nature of the research question will generate data that lends itself to inductive analysis rather than statistical testing. Qualitative research respects the uniqueness of individuals,

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[125] He advocates alternative approaches to the empirical quantitative research methodologies which dominate the research areas of religion, spirituality and ministry (1996, p. 201). Myers suggests a "pro-active" research stance where researchers employ research tools from various research methodologies to facilitate "useful" research, by which he means research which is not dispassionate and which is tied closely to the context of the research (1996, p. 203).

[126] They include: feminism, ethnography, Marxism, cultural studies, critical theory, grounded theory, phenomenology, hermeneutics, rhizomatics, deconstructionism, textual analysis, psychoanalysis, literary theory, narrative, semiological and content analysis, discourse, archival and phonemic analysis and even statistical analysis (Denzin & Lincoln, 1994b; cited in Morrison, 1997, p. 240, fn. 11).

permits investigation of family processes, and it allows for verbal analysis of a text rather than mathematical testing. Qualitative analysis enables researchers to identify the areas of agreement and disagreement between participants' responses and to isolate the themes that knit the data together into a narrative. In this way the researcher can formulate a model that accommodates the variety of data.

Qualitative methodology combines readily with other research methodologies.[127] This research project is primarily an ethnographic study (a qualitative methodology) of a group of parents in a Faith and Light community that uses participant observation at monthly community meetings, open-ended interviews, and focus group discussions, to gather data. I relate the experiences of parents to research and theoretical literature on family systems, the life cycle, stress and coping, grief and family belief systems. This is a dialogical process between experience and related social science theory. The second part of the study explores the extent to which a theological pastoral care and counselling measures and is measured by what happens in a local Faith and Light community. It locates the findings from the ethnographic study and their interaction with relevant social science theory within the overarching Christian metanarrative from which a theological pastoral care and counselling is interpreted and delivered.

Focussed Ethnography – a Qualitative Methodology

Quantitative research revolves around a statistical analysis of variance. Ethnographic research as a qualitative method concerns itself with the "insider's" experience of an event. It highlights the influence of context on thought and behaviour. The Greek words *ethnos* (which translates as "race, tribe or people"), and *graphein* (meaning "to write")

[127] Sprenkle and Moon (1996, p. 5) advocate methodological pluralism in family therapy research, with respect for, and acceptance of, different inquiry paradigms. They argue that qualitative methods can complement quantitative ones. Critics of traditional quantitative research as it applies to family therapy research, such as Tomm (1986) argue that its assumption of a linear causality is out of keeping with systems thinking, that it fails to account for the impact of the observer on what was being observed, and that its approach is "reductionistic." Defenders such as Gurman (1983) have countered with the assertions that more recent quantitative techniques are applicable to systemic processes, that the methodology is widely recognized and respected in the scientific community, and that it is a reliable indicator of the efficaciousness of the technique being examined.

form the roots of *ethnography*. [128] Marcus and Fisher (1986) have defined ethnography as a research process in which "the anthropologist closely observes, records and engages in the daily life of another culture – an experience labelled as field-work method – and then writes accounts of this culture, emphasising descriptive detail" (p. 18). As a methodology it allows researchers to access the conceptual models of participants. It is for this reason it seemed that from amongst the various qualitative methodologies, ethnography would provide the most adequate fit.

Essential Features and Underlying Assumptions

It is probably helpful to identify the underlying assumptions of ethnography. First, culture as a system of knowledge shapes human perception and behaviour. Second, people's experiential world reveals itself through their use of language. Third, human experience is context-dependent. Fourth, the emic (insider's or native) cultural perspective prevails over the etic (outsider's or researcher's) perspective. Fifth, one's frame of reference inevitably colours "facts." Sixth, ethnographies are tentative in that phenomena are "investigated" rather than accessed directly (Newfield et al., 1996, pp. 28-29).

Ethnographic research is inherently inductive rather than deductive, and recursive rather than linear. Often the research focus can shift during the investigation. There are various methods of data collection, including participant observation, interviews, case studies, conversational analysis and life narratives. In this instance, I have used participant observation, informal interviews and focus group interviews. Newfield et al. (1996, p. 30) identify three fundamental paradigms in ethnography: "holistic" or "old," where the researcher studies the culture of a single community as an integrated whole; behavioural, where the researcher measures variance from identified cultural patterns of behaviour; interpretive, where the ethnographer focuses on symbols, meanings and worldviews of a culture. In this case I sought to access the experience of parents with emphasis upon how they construed their experience. The closest fit is probably the interpretive paradigm.

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[128] Crane, J., & Angrosino, M. (1984). *Field projects in anthropology.* Prospect Heights, IL: Waveland Press. Cited in Newfield et al. Cited in Sprenkle and Moon (1996, p. 26).

Focus Groups as an Ethnographic Methodology

Definition

I have chosen to use focus groups as the primary means of data collection in this ethnographic study. Morgan (1997) defines focus groups as "a research technique that collects data through group interaction on a topic determined by the researcher" (p. 6). [129] Five characteristics of focus groups include: (a) comprised of participants; (b) participants have shared characteristics; (c) provide qualitative data; (d) involve focussed discussion; (e) help to understand the research topic (Krueger & Casey, 2000, p. 5). A moderator facilitates the discussion, focussing the participants on the research question. Focus groups generate responses that might not occur in individual interviews through open-ended questions and through the synergetic impetus of group interaction (Piercy & Nickerson, 1996, p. 174).[130] It is this interactive component yielding particular data that some authorities regard as definitive of focus groups.[131]

Historical Perspective

Focus groups have evolved over the last century. Frey and Fontana (1993) report that Emory Bogardus used group interviews as early as 1926. It is generally recognised that focus groups as a particular genre had their origins in the work of Robert Merton in his analysis of Army training and morale films during World War II. It seems that their use is becoming more widespread. From a review of on-line databases, Morgan (1996) reports

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[129] Greenbaum (1988; cited in Frey & Fontana, 1993) defines the focus group interview as "a research technique that includes eight to ten persons brought to a centralised location to respond to questions on a topic of particular interest to a sponsor or client." Albrecht et al (1993, p. 53) describe focus group discussion as a means of gathering in-depth information on a research question. Krueger and Casey (2000) regard focus group study as "a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (p.5). While some have sought to define a focus group as a type of group interview (e.g. Frey & Fontana, 1993), I prefer Morgan's (1997) perspective that casts focus groups as a particular research technique.

[130] Furthermore they note that it is a methodology that accommodates the epistemology of the researcher whether positivist, postpositivist, constructivist or otherwise.

[131] Morgan (1997) maintains that "the hallmark of focus groups is their explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group" (p. 2).

that whereas focus group research was almost unknown in the 1980s, more than 100 articles per year are now appearing in academic journals.

Uses of Focus Groups

Focus groups were originally used as means of testing market response to commercial products. They are now used to gather data and to evaluate research in qualitative studies (Sprenkle & Moon, 1996, p. 10).[132] Schatzman and Strauss (1973; cited in Frey & Fontana, 1993, p. 25) [133] maintain that group interviews work where relationships between participants are complex and diverse. "In addition, this form of information gathering provides an especially nice situation for revealing variations in perspective and attitude and a ready means, through subtle pitting of one against the other, for distinguishing between shared and variable perspectives" (p. 82). As the research question explores in depth the perspective and the experience of parents it seemed that focus group methodology was the most adequate fit.

Focus groups may be self-contained, serving as the principal source of data; they may supplement another primary method; or they may partner with others in a true sharing of methodologies (Morgan, 1993, p. 3). The determining factor in whether to combine other methodologies is whether the data produced from the focus groups form an adequate body of knowledge (Morgan, 1997, p. 21).[134] Focus groups linked with participant observation as used in this project allow insight into participants' thought on a particular topic. Most combinations of methodologies currently use focus groups to supplement better known qualitative research techniques. In this project I am treating the focus group

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[132] Frey and Fontana (1993, pp. 23-26) clarify different purposes of group interviews: the exploratory phase of a research project, pretesting of questionnaires or other phenomena, triangulation with other data collection techniques, and phenomenology.

[133] Schatzman, L. & Strauss, A. L. (1973). *Field research: strategies for a natural sociology.* Englewood Cliffs, NJ: Prentice-Hall.

[134] Focus groups may be combined with individual interviewing to assist with formulating either the individual or group questionnaire, to understand differences between potential participants or interviewees, and to follow up use of either methodology. In this last instance use of a focus group after individual interviews permits the researcher to explore issues that became apparent only after analysis of the interviews, and follow-up individual interviews after a focus group can provide additional detail on topics touched on briefly in the group. In combining research methods, the researcher aims to bolster the overall research project, irrespective of the primary method used (Morgan, 1997, p. 23).

as largely self-contained,[135] although I have supplemented it with a number of individual interviews, along with field notes from participation/observation at meetings. Rather than argue for the supremacy of one methodology over any other, I assert the usefulness and relevance of a number of methodologies.

Rationale for Use

Focus groups are now used in a variety of social science settings and may take many different forms. Clearly, the purpose of the research needs to fit with focus group methodology. "The simplest test of whether focus groups are appropriate for a research project is to ask how actively and easily the participants would discuss the topic of interest" (Morgan, 1997, p. 17). It seemed to me that the parents selected would be open to discussing the research question in a safe and comfortable environment.[136] The parents themselves indicated their willingness when I approached them at a preliminary stage.

It is vital to determine and to specify the purpose of the focus group (Krueger & Casey, 2000, p. 21). In this instance the purpose of the group was to canvass parents' perceptions of Faith and Light's influence on their families' life at the launching stage. I have chosen a focus group methodology because I wanted to explore participants' range of experience, to understand differences in their perspectives and to discover factors that influence their perceptions (Krueger & Casey, 2000, p. 24). Researchers hold that focus groups facilitate investigation of complex behaviour and motivations, for which there may not be another readily available forum. Hearing others share thoughts and feelings, can help some people to identify and articulate their own views (Morgan & Krueger, 1993, p. 17). Focus groups are recognised as a friendly research method that is respectful and not condescending, and they enable researchers to gain a better understanding of the participants' points of view (Morgan & Krueger, 1993, p. 18). In summary, I am seeking to understand a phenomenon from the point of view of a group of people who have

[135] Morgan and Krueger (1993, pp. 9-10) make the point that one of the *myths* of focus group research is that it needs to be validated by other research methods.
[136] It is important to create an environment where people feel comfortable in expressing their thoughts and feelings (Morgan, 1997, p. 27).

experienced that phenomenon. Use of focus groups is a practical fit (Piercy & Nickerson, 1996, p. 175).

Indices of Quality

Krueger (1993) writes from his experience as a market researcher rather than an academic researcher. Nonetheless his indices of quality control in the two related dimensions of researcher competence and participant perception have general application for focus groups. The ten factors he identifies are: (a) clarity of purpose; (b) appropriate environment; (c) sufficient resources; (d) appropriate participants; (e) skilful moderator;[137] (f) effective questions; (g) careful data handling; (h) systematic and verifiable analysis; (i) appropriate presentation; (j) honouring the participant, client and method. It was important in this research project to pay particular attention to these domains.

Strengths and Weaknesses

Morgan (1997, p. 13) argues that the strengths and weaknesses of focus groups are a corollary of their distinctive attributes: reliance on the researcher's focus, and group interaction. Piercy and Nickerson (1996, p. 182) include a table documenting the weaknesses and strengths of focus group research, where they maintain that a focus group format through the synergistic group dynamics generates a greater variety of ideas and information than individual interviews. Morgan (1997, p. 14) on the other hand reports that the claimed "synergistic" effect of group interaction remains largely untested. [138] Nonetheless, focus groups are relatively efficient in terms of gathering equivalent amounts of data in comparison to individual interviews.

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[137] He summarises his advice for novice moderators. "Be sincere, agonise over the questions, and actively listen to responses. Allow sufficient time for analysis, don't work alone – seek feedback from colleagues... you are there to learn from others" (Krueger, 1993, p. 84).

[138] Fern (1982) has tested for information generation. Her studies revealed that group interviews did not generate more or better ideas than an equivalent number of individual interviews. See Fern, E. F. (1982). The use of focus groups for idea generation: the effects of group size, acquaintanceship, and moderator on response quantity and quality. *Journal of marketing research, 19,* 1-13. Cited in Morgan (1997, p. 14).

The principal argument in favour of focus groups is that group interaction generates reporting on experiences and perspectives that would not otherwise be accessible. In particular, the researcher can observe the manner in which participants respond to one another as they share and compare their views. This permits direct evidence of how participants themselves interpret their similarities and differences (Morgan, 1997, p. 20). Focus groups permit the researcher to encounter more participants; they are flexible and allow in-depth questioning; they provide an understanding of the social relationships between participants, and with wider systems within the ambit of the research project (Frey & Fontana, 1993, p. 33). Albrecht et al. (1993, p. 54) argue that the interactional dynamic of focus groups might generate data that is more "ecologically valid" than that from individual interviews in "asocial" settings. They note that social interaction affects not only opinion formation but opinion articulation as well.[139] The format is reasonably flexible and open-ended questions allow for creative and spontaneous responses. It enables the researcher to deal with potentially sensitive issues and findings can be triangulated with other data increasing the size of the qualitative study.

Participants appear to enjoy the focus group experience; the results are available quickly and are easy to understand. While the data from group interviews remains subjective and interpretive, Frey and Fontana (1993) note that group interviews through their "polyphonic" nature and their diffusion of the potential influence of the interviewer are a response to postmodernist criticisms of individual interviewing. By relying on the researcher's focus it is possible to generate data on precisely the topic of interest, a decided advantage over participant observation (Morgan, 1997, p. 13). Krueger & Casey (2000, p. 161) note that recent academic interest in focus group methodology has brought strengths in individual interviewing and content analysis. Academic researchers have introduced openness in methodology, rigour in analysis, and accountability through peer

[139] Kelman (1961) identifies three processes of opinion generation: compliance, or responding as expected in anticipation of immediate reward; identification, or holding a similar position to an admired other; and internalisation, or reporting on personal convictions. The moderator needs to facilitate the expression of internalised opinions. Albrecht et al. (1993, pp. 61-62) advise researchers to consider the entirety of the focus group discussion when interpreting data and to recognise that social influence through compliance, identification or internalisation will have an impact.

review. Finally, it is worth noting that focus groups are well suited to interdisciplinary research (Morgan, 1997, p. 236).

Piercy and Nickerson (1996, p. 182) summarise some of the shortcomings of focus group research. They include the reduced control the researcher has over the direction of the discussion, the potential for researcher bias to influence data through verbal and nonverbal cues[140] and the likelihood that participants' responses are not independent. It is not possible to ensure participant anonymity, and dominant participants clearly influence the results.[141] The focus group method does not lend itself to traditional understandings of reliability and validity.[142] The volume of data generated poses challenges for organisation and interpretation. Frey and Fontana (1993, p. 33) add that the moderator needs to possess group facilitation skills and be sensitive to group dynamics, the influence of relations outside the group on responses within the group, and the effect of group size on participants' contributions. Moderators invariably tread a fine line between being sufficiently directive to elicit responses to the research questions, while allowing participants the freedom to express spontaneously their own experiences.

Focus groups do not have the generalisability of quantitative research, based on random samples, nor the naturalness of qualitative research, based on field work (Morgan, 1993, p. 228). In relying on self-reported data, there may be omissions where participants forget or intentionally conceal. Morgan notes that triangulation for testing the validity of focus group data is both expensive and time-consuming.[143] Albrecht et al. (1993) argue that the

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[140] It need be stated that researcher's influence on data is an issue in nearly all qualitative research (Morgan, 1997, p. 14).

[141] Originally academics were concerned about *contamination* in focus groups, where strong voices influenced others (Krueger & Casey, 2000)

[142] The purpose of the research was not to determine whether the influences the participants identified were important for *all* families. Nonetheless reliability *of process* is important in both conducting the focus group and analysing the data. As to validity, I sought to understand the participants' perceptions. Therefore, the validity of the research depends upon the extent to which it reflects accurately the views, or the perceived reality of the participants.

[143] Other approaches for testing the validity of focus group data include: participant checks, where the researcher seeks their response to research results; and audits or external reviews of the procedures by which conclusions are drawn from the data collected (1993, p. 233). The second focus group with the original participants was to discuss findings with them. Another option would have been to conduct individual interviews to validate what each participant had said.

communication process can affect the nature and quality of data arising from the focus group discussion, and can influence the opinions generated.[144]

Summary

"The past decade has produced a steady increase in social scientists' use of focus groups, and there is a widespread consensus that focus groups are a valuable technique for collecting data" (Morgan, 1997, p. 71). There are various ways of doing focus group research. Using Morgan's criteria, I have sought in this study to promote the integrity and quality of the data generated from the focus groups through defined research goals, a clear questioning route, careful selection and recruitment of participants, comprehensive analysis of data, and through attentive moderation.[145]

Participants and Methods

My aim was to explore the influence of Faith and Light on families of offspring with an intellectual disability. As chaplain to a local community of Faith and Light over a period of two years, I recognised that the group would provide a ready and accessible source of family experiences. As the project developed it became clear that the influences of Faith and Light would likely vary across the family life cycle, and that families themselves would be dealing with related but very different issues at the various phases of their developmental life. For this reason I decided to focus on one particular phase of the family life cycle, the transition or launching phase, often recognized as the most challenging time in a family's life. It is during this period that young adults leave the family nest.

The three principal methods of data collection included: participant observation at monthly community meetings; open-ended interviews; and focus group discussions.

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[144] They identify communication phenomena that may affect data validity: social desirability and sensitivity of subject matter, lack of trust in moderator or other participants, deception by participants, and researcher bias (1993, p. 63).

[145] Although popular opinion holds that moderator skills determine the success of focus group research, it is rather the soundness of the choices that researchers make throughout the project, which is most influential.

Participant/Observation

I kept field notes from participation in, and observation of, monthly group meetings of a Faith and Light community, four national annual meetings, two zone meetings held every two years, and an international meeting held every four years. Monthly meetings generally attract around 30 people. Over the course of the period from July 2000 to June 2004 I attended monthly meetings regularly in my capacity as chaplain. The local group that I was part of, consists of people with an intellectual disability, some of whom continue to live with their parents, some of whom are living in group homes, and some of whom live independently. There are often people with an intellectual disability from the local L'Arche home accompanied by assistants. Some parents attend, as well as friends of people with an intellectual disability, and caregivers who work in group homes. I did not take notes when I was present at the meetings. Rather, I participated as fully as I could in the meetings, including giving some simple Bible teaching, leading small groups and assisting with the liturgy. I noted significant experiences afterwards. I believed it important to be immersed in the culture of the community as a chaplain, in order to understand better the experiences of the parents. I was not interested so much in my experience of the movement, as in the experience of families as articulated by the parents.

The national meetings involved representatives from communities in the geographical region known as Canada West gathering over a weekend in Mississauga (2001), Saskatoon (2002), Waterloo (2003), and Winnipeg (2004). The zone meeting was held over three days and involved national coordinators and chaplains from the four regions that make up the zone of North America (2002, 2004). The international meeting brought together over 250 delegates from the 75 countries in which Faith and Light is represented for a week near Rome in Italy (2002).

Open-ended Interviews

I conducted ten open-ended interviews with people intimately associated with Faith and Light: the two cofounders of the movement; the international coordinator; the

international chaplain; a national coordinator; two community leaders, one of whom was a parent of a daughter with an intellectual disability; chaplains to two communities; and a theologian who was also a parent. I took handwritten notes in each of these interviews and/or audiotaped them, and prepared typed transcripts afterwards. The purpose of these interviews was to explore the experience of Faith and Light from a variety of perspectives and to identify different perceptions of the possible influence of Faith and Light on families from these perspectives. The interviews took place in a variety of settings: at national and international meetings in convenient locations, at a L'Arche home, in a private home, and in a park. Pragmatic considerations generally dictated the location.

Focus Groups

Planning and research design.

There are four phases of qualitative research: planning, observation, analysis, and reporting (Morgan, 1997, p. 31). Focus group studies require careful preparation. Morgan emphasises planning as it is the phase that differs most from other qualitative methodologies. The design depends on the purpose of the focus group. It can range from groups requiring maximum flexibility where the number of groups to be held and even the characteristics of participants is decided as the research progresses. More structured approaches work well where there is a clear agenda for the research; less structured approaches favour exploratory research. In this instance, where I had sought specific ethnographic information in an area with which I was reasonably familiar a detailed design prepared in advance was more appropriate (Knodel, 1993, p. 36). An important factor is to balance the design of the research project with the time and other available resources for the study. It is wise to elicit feedback from colleagues, researchers and prospective participants on the research design (Morgan, 1997, p. 37).

Formulating guidelines and developing a questioning route.

The first step in designing this focus group was to define concepts and clarify the issues I sought to explore. The concepts need to be cast as a set of discussion guidelines which I used during the sessions. The question structure can vary between an unstructured and open-ended format to one that is formalised and structured. I used a semi-standardised questionnaire, which falls between a fully standardized interview and one that is completely unstructured. Semi-standardized interviewing aims to optimise participants' and researchers' understanding of each other (Berg, 1989). Open-ended questions and the use of participants' terms for concepts and feelings enhance the data collection process (Kidder & Judd, 1986; cited in Morrison, 1997, p. 21). They provide a means of exploring further participants' comments, and of stimulating discussion on issues that participants may not have anticipated.[146] In addition, I asked spontaneous questions to invite elaboration on participants' experience where it was relevant to the research question.

Good questions have certain characteristics. They are conversational, making use of participants' terms. The questions are easy to pose, clear and short. They are open-ended, and ask one question only.[147] A sound questioning route begins with easy to answer questions, moves sequentially from general to specific questions and weights each question for time.[148] Krueger and Casey (2000, p. 44) differentiate between the different types of questions: opening, introductory, transition, key and ending. I have structured the questioning route for the first focus group according to this schema (see Appendix H).

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[146] It is important to keep guidelines reasonably brief. They are best kept general, open-ended and exploratory without inquiring directly about the participants' specific situation (Knodel, 1993, p. 37).

[147] Krueger and Casey (2000) make further suggestions. It is possible in a focus group to ask people to list items, or to rate them according to a given scale. Questions that invite participants to reflect on their experience can be helpful. It is better to frame questions positively rather than negatively, and to use un-cued questions before cued ones. Testing questions with people before using them in the focus group may prompt some helpful changes. Krueger and Casey identify two essential techniques for moderators: the pause, and the probe question.

[148] Morgan (1997, pp. 39-41) refers to this as the "funnel strategy." It begins with a less structured approach to invite free discussion, and moves to more structured discussion of specific questions.

Selection and recruitment of participants.

In selecting participants, the aim is to minimise sample bias rather than achieve generalisability (Morgan, 1997, p. 35). The researcher seeks a balance between enough variation for contrast, and sufficient similitude that participants will not be inhibited. Homogeneity in background rather than attitudes is desirable, the overriding criterion being whether participants can comfortably discuss the research question in ways helpful for the researcher. It is a myth that focus groups need consist of strangers (Morgan & Krueger, 1993, p. 6). I have identified participants who are *information-rich,* [149] namely the parents. In this instance, selection was reasonably straightforward. I wanted to limit the study to a single Faith and Light group. To invite participants from various Faith and Light groups would introduce the variable of differences between groups, which would obscure the research purpose. In addition, concentrating on the one group with which I have been associated allowed me to use participation/observation data.In this study I used basic *purposive sampling*[150] to select those participants who were available and could provide sufficient and relevant information. It entailed creating a list of attributes fundamental to the research question. The participants needed to be parents of adult offspring and members of a single Faith and Light community. I approached the coordinator of the local group to seek her permission for conducting the study. Afterwards I checked informally with the parents I had selected to see whether they would be willing to be part of the study. All of them expressed willingness. The demographic characteristics of the participant parents and the living arrangements for their offspring appear in Table 2. I have changed all participants' names and other identifying characteristics.

[149] Information-rich participants are "those from which one can learn a great deal about the issues of central importance to the purpose of the research" (Patton, 1990, p. 169).
[150] Purposive sampling is appropriate where the researcher seeks data from a particular group and uses a rational method for selecting participants (Nelson, 1996, p. 455).

Table 2

Demographic Characteristics of Parents and Offspring with an Intellectual Disability

Name[a]	Age	Marital status	Religious affiliation	Ethnic heritage	Offspring by gender/age[b]	Living arrangements by age for offspring with an intellectual disability
Wendy & Jack (Peter)	69 79	Married	RC	UK/ European	F 45; M 44; M 42; M 38*; F 32; F29	Family home (< 30) Group home (30-34) Family home (34-37) Christian residential community (37+)
Vicky (Ursula)	72	Widowed	RC	Hungarian	F 38*	Family home (since birth)
Paul & Tina (Henry)	76 67	Married	RC	European	M 33*; F 29	Family home (birth-17) Institutions (17-27) Group home (27+)
Hugo & Julie (Maria)	77 73	Married	RC	UK/ European	M 54; M 51; F 49; F 47; F 35**	Institutions (< 13) Family home (13-30) Christian residential community (30+)
Kevin[c] & Frances (Cassie)	65 60	Married	RC	UK/ European	F 36; F 35**; M 34	Foster home (< 4) Family home (4+)

Note. RC = Roman Catholic; F = female

[a] Name of offspring with an intellectual disability in parentheses. [b] Biological offspring with an intellectual disability indicated with single asterisk; adopted offspring with an intellectual disability indicated with double asterisk. [c] Kevin and Frances were present only for the third focus group meeting.

I began the process of seeking approval for the research proposal from the Wilfred Laurier University Research Ethics Committee. This entailed submitting a request for "Ethics Review of Research Involving Human Subjects" accompanied by copies of an information letter, informed consent statement and the proposed focus group questions. The Committee required further clarification of, and minor alterations to, the original application. After providing clarification and making the proposed changes, the Committee deemed the proposal "ethically sound" (see Appendix D). After securing the Committee's approval I circulated the informed consent statements to the parents, with a copy of the proposed questions.

Size of group and number of sessions.

The amount that each participant has to contribute is an important factor in determining the size of the group (Morgan, 1997, p. 42).[151] In groups with fewer than six participants, discussion may be difficult to sustain: in groups with more than ten, discussion may be challenging to control. In this instance there were four sets of parents and a single parent who attended Faith and Light meetings regularly. Of these, three sets of parents and the single parent were willing and available to participate in the focus group. One parent was not well enough to attend either focus group. That left six participants for the first two focus groups. During the third focus group, one further set of parents joined in, as well as the one parent, who had been ill for the first two groups. The number of participants worked well in practice.[152]

Because I had chosen to limit research to one Faith and Light community, there were only enough potential participants to conduct one focus group. With only one group, it is difficult to know whether the discussion simply reflects an unusual mix of participants or whether the participants have peculiar circumstances (Morgan, 1997, p. 44). That remains one of the risks of this research. I decided that we would meet twice so that I would have the opportunity to feed back to the participants the significant issues that I saw arising from the first group. We would also have the opportunity to discuss questions not touched on in the first group, and to explore other questions in greater depth. The general rule is that one conducts only as many groups as is necessary to respond in good faith to the research question (Morgan, 1997, p. 44). The goal is *saturation*, where further data collection no longer generates new insight. It seemed to me that after the second group

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[151] While it is difficult to predict how much each participant will speak, Kelleher (1982) estimates that 40% of participants will contribute easily, 40% will open up if the situation presents itself, and 20% will rarely share. It is recommended that shy participants are seated directly across from the moderator to facilitate eye contact, and that garrulous participants are seated next to the moderator to allow for control through use of body language if necessary. It is important that the assistant moderator make written notes on the extent of different participants' contributions. See Kelleher, J. (1982). Find out what your customers really want. *Inc, 4,* 1, 88-91. Cited in Krueger & Casey (2000, p. 104).

[152] Krueger & Casey (2000) maintain that the ideal size for non-commercial topics is six to eight people. Smaller groups facilitate more in-depth exploration of intense experiences. They also suggest that incentives help. I offered a small gift to each set of parents after the first group and arranged for lunch to be provided after each group.

we had reached saturation. The participants decided amongst themselves to continue meeting together every three to four months. They invited me to be part of their gathering, which occurred five months after the second focus group. There were an additional three parents present: one couple who were members of the Faith and Light group, and who had not attended the previous focus groups; and the spouse of one of the original members of the focus group. I audiotaped and transcribed this third meeting. While members did raise new issues, they were elaborations upon themes that had been raised in the previous two focus groups, and fell within the table of themes I had already prepared. The third meeting confirmed that there were no new insights emerging, and that data saturation had been attained. It is important to recall that in ethnographic studies, the researcher seeks to generalise to a *theory* rather than a *population*. It need be added that practical considerations such as budget and time constraints also influence the number of sessions.

Setting.

Focus groups can take place in a formal pre-arranged setting or in the field, often referred to as natural setting (Frey & Fontana, 1993). In a prearranged setting, the environment needs to be nonthreatening, convenient and comfortable (Krueger, 1993, p. 68). In this instance I invited people to a private meeting room in a church, where we sat around a table.[153] Light refreshments were within easy reach.[154] I ensured that windows in the doors were covered to protect the identity of participants' as far as was possible. The assistant moderator sat at a separate table monitoring the recording equipment and taking notes.

Ethical considerations in focus groups.

Each participant in the focus group received an information letter which set out the purpose of the research, the proposed questions, details around the focus group process,

[153] A table for the participants is the most basic element of the site (Morgan, 1997, p. 55).
[154] One of Krueger and Casey's (2000) tips was to serve quiet food on paper plates with plastic cutlery in order to minimise the impact on recording quality!

the parameters within which the data from the focus group would be used, the potential risks and benefits associated with participation in the focus group, information around confidentiality and participation, and contact details (see Appendix E). Each member signed an informed consent statement (see Appendix F). I relied primarily on audiotapes to construct the data from the focus group, supplemented with typed notes taken by the assistant moderator during the group and with a transcription of the postsession debrief with the assistant moderator. The audiotapes were transcribed. Participants had the opportunity to withdraw from the group at any stage in the process. The audiotapes were erased after transcription and the transcribed verbatim report was destroyed after completion of the research.

It is difficult in qualitative studies to guarantee the anonymity of participants owing to their unique histories. It is likely that people who know the participants will recognize their stories. In a group situation, it becomes even more difficult where the researcher has no control over what participants say outside the group setting. While researchers need to make reasonable efforts to ensure confidentiality, there is an ethical obligation to advise participants that anonymity cannot be guaranteed.[155] I sought agreement from participants' that they would not divulge the identity of members, nor the content of the discussion. I preserved participant anonymity in the transcribed material by replacing participants' names with numbers and removing any identifying features. When it came to writing the description of findings, I substituted pseudonyms for the numbers. In addition, researchers owe a duty of care to participants in the research project. They need to provide for their safety, and to ensure that any pain or trauma arising in the course of the project is dealt with. I stated in the information letter that while there were no major risks in this research, there was the possibility that participants might disclose personal information that would leave them feeling uncomfortable. I declared that participants had the right to decline to participate further in the discussion at any time, and that I would offer support, and if necessary make referral to an appropriate professional.

[155] See also Guilbault (2000, p. 77).

Data Collection, Data Reduction and Preliminary Analysis

In qualititative methodology these three phases of the research process tend to meld together. Although the bulk of the data collection occurs at the outset, and analysis happens towards the end, preliminary data reduction and analysis commences as soon as data is collected. The two principal methods of data collection in ethnographic research are participant observation and ethnographic interviewing. Both methods are inductive, discovery-oriented, and seek to map the characteristics of a culture. They complement each other by exploring behaviour *and* cognitions (Newfield et al., 1996, pp. 34-35). Participant observation at the community meetings, national, zone and international meetings, the open-ended interviews with individuals, and the focus group discussion are primarily data collection activities. Taking hand-written notes, transcribing those notes and transcribing audiotapes involve the reduction of data. Generating categories, developing codes, coding sections of the transcript, and grouping together similarly coded sections probably involves both data reduction and preliminary data analysis. The researcher's thought during this time both reduces and analyses data. Developing questions to be used in subsequent focus groups is an analytical activity (Guilbault, 2000, p. 80).[156]

In ethnographic research, because of the volume of potential data, the researcher needs to decide what to notice (Newfield et al., 1996, p. 34). This study explores the influence of Faith and Light on families. I decided to pay close attention to participants' stories.[157] Stories are the currency in a narrative hermeneutical methodology. Listening to the stories people tell about themselves and about others is a means of understanding their stance in the world. Vanier believes that truth is discovered and revealed in community (J. Vanier, personal communication, September 25, 2002). It made sense that the

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[156] The question I kept before me in participant/observation, in individual interviews and in focus groups was, "What is happening here?" It leads to the ethnographic and phenomenological question "What does this mean to the participants?"

[157] Morrison (1997, p. 26) believes that the success of the interviews he conducted in his qualitative study was attributable in part to having participants tell their story as opposed to having to analyse themselves or others.

collection of data through participant observation, informal interviews and focus group discussion as far as possible be a community event.

Moderating the Focus Groups

A moderator facilitates group discussion and often works with an assistant who looks after practical matters.[158] I chose to moderate the focus group myself which provided the opportunity not only of getting to know the participants, but of becoming intimately involved with the data from the outset of the collection process. The literature emphasises moderators' need for empathy and positive regard.[159] Moderators listen, value diverse opinions, and withhold their personal points of view. They remember well, and are sincere, flexible, warm and humorous (Krueger, 1993, p. 73).

The introduction is critical.[160] Moderators welcome participants, give an overview of the topic, set out ground rules, set the tone of the discussion and introduce the first question.[161] The main purpose in beginning discussion is to elicit a meaningful response from each participant (Morgan, 1997, p. 49).[162] Moderators facilitate others' discussion

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[158] An assistant moderator takes comprehensive notes, operates the tape recorder, helps with practical matters (eg. seating, lighting, heating, refreshments), and responds to unexpected interruptions. The moderator may invite the assistant to ask any additional questions at the conclusion of the group, and to summarise briefly key points made during the discussion. The assistant moderator plays a key role in post-session analysis (Krueger & Casey, 2000, p. 101).

[159] For example, Krueger & Casey (2000, p. 97) maintain, "Moderators' respect for participants may be one of the most influential factors affecting the quality of focus group results." Albrecht et al. (1993, p. 62) emphasise the influence of the moderator's experience, competence and style in facilitating group interaction, and her or his degree of involvement in the process, on the quality of the data generated. This needs to be weighed with Krueger's earlier statement, where he co-wrote that it is more important to define the purposes of the project and who the participants will be, than to overemphasise the skill requirements of the moderator (Morgan & Krueger, 1993, p. 5).

[160] The moderator's introduction has a significant bearing on the quality of the group (Krueger, 1993, p. 74).

[161] The first question is designed to have all participants contribute, to emphasise their common characteristics, and to be capable of being answered briefly and factually (Krueger & Casey, 2000, pp. 107-108).

[162] He continues to give examples of how to initiate discussion. He suggests that it might help to have each person take several minutes to make some written notes before responding to the question that opens discussion. This question needs to emphasise participants' interests and invite their perspective. After ten minutes of open discussion the moderator moves the discussion to the first substantive topic with a statement such as, "One aspect I've heard several people mention is... I wonder what others' experience of this has been?" If the topic has not been raised, the moderator could introduce it by observing, "I am

and the questioning route guides interaction without forcing it. The questioning route or interview outline is a tool to balance researcher focus and group discussion (Morgan, 1997, p. 48). Moderators use verbal and nonverbal cues to elicit relevant discussion, and to curtail what is meaningless to the study (Krueger, 1993, p. 76). Good preparation is essential, which includes familiarity with the introduction and with the questioning route, with key questions and with time to be spent on each question.[163] While I devoted considerable time to preparing a questioning route, and familiarizing myself with the questions, I found that it was important to allow the group to move in the direction it wished to go. This was especially evident when a participant raised a sensitive issue in the second group. In summary, effective focus group interviews span the range of relevant topics, provide specific data, elicit participants' feelings in depth, and account for the personal context of individual responses (Merton et al., 1990).

Each meeting of the focus group was recorded. I invited the parents gathered to reflect on their experience of raising children with an intellectual disability. After parents had signed the informed consent statements, I introduced the focus group by setting out some basic ground rules (see Appendix G) and by re-emphasising the need for confidentiality. I began our discussion with an open-ended question to allow parents to ease themselves into the discussion. The focus group literature had recommended moving from general questions to more specific questions (see Appendix H). Towards the end of the session I invited the assistant moderator to summarise the main points which had arisen, and I checked with participants on their accuracy. I concluded the focus group by asking participants if there was anything else that they wanted to add which they thought or felt had not been discussed. I thanked the participants, we set a date for our next meeting and we broke for a shared lunch. After the meal the assistant moderator and I debriefed the focus group together, the assistant moderator contributing her reflections from notes she had taken. I recorded our shared reflections, which were later transcribed.

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surprised that no one has mentioned... Is it a significant issue or not?" At the same time Krueger and Casey (2000) warn against inviting questions from participants at the beginning of the focus group.

[163] At the same time, moderators may be too familiar with the research area. Krueger (1993, pp. 74-75) warns that a moderator can be too well-informed of the subject matter, which risks premature categorisation of view points, and promotion of a particular stance on the research question that may influence participant responses.

The Transcription Process.

Transcription was a team effort. The assistant moderator undertook to transcribe our debriefing sessions. The transcript of the first focus group debrief numbered 28 pages (double-spacing) and the second was 45 pages. She also produced typed summaries of notes she had taken during the focus groups. I employed another person to transcribe small sections of both focus groups, which I revised and amended afterwards. I transcribed the bulk of both focus groups. During and after transcription, I replaced the participants' names with pseudonyms. I inserted line numbers, created a margin to facilitate the coding process and used 1.5 spacing for the document. The first focus group transcription ran to 70 pages (94 pages double-spacing) and the second focus group transcription numbered 56 pages (74 pages double-spacing). The transcription of the third group meeting filled 41 pages (55 pages double-spacing).

Emerging Themes and Follow-up Questions

After the first focus group I reviewed transcripts of the focus group and the debriefing session to identify themes that had suggested themselves initially (see Appendix I). I divided the themes into two sections: those pertaining to parenting, and those pertaining to Faith and Light. I circulated this summary to the participants at the second focus group and used it as a springboard for discussion. While transcribing the audiotapes from the first focus group, I noted follow-up questions for the second gathering. These questions included clarification of vague responses to initial questions, repetition of issues not covered adequately or at all in the first group, and further probing of relevant topics raised.

The Second and Third Focus Groups

The second focus group took place three weeks after the first gathering. I circulated a summary of the emerging themes from the first group, and invited members to read it and to comment on it (see Appendix I). I wanted to ensure that I had captured the tenor of our

original discussion. Participants made some initial comments, and referred to the summary during the course of the second group. I sought to ask those questions that I had composed during the transcription of the first focus group (see Appendix H). Members of the group had other issues they wanted to discuss. Discussion of one incident (which the participant concerned asked to be removed from the transcription) dominated a significant portion of the focus group.

I believe that it was important to conduct a second group. The first focus group provided a forum in which participants were able to tell their own stories and make spontaneous contributions. My intent was to be more directive in my questioning in the second group. Having a second gathering permitted me to reflect on the first group discussion, and to prepare more probing questions. The participants were able to respond to the identified themes from the first focus group. As it turned out, given the issues raised by group members, it seemed to be more important to provide participants the space to share their stories, and to allow other members to respond.

The third group meeting occurred approximately five months after the second focus group. Participants had expressed interest in meeting three or four times a year to continue dialogue. One of the participants volunteered to hold the meeting in her home. An additional three parents joined us. The format was similar. We met around a table for about two hours, and shared lunch together afterwards. I circulated the seven themes that I had identified from the previous two focus groups, and allowed discussion to develop. With the permission of the group I audiotaped the discussion, which I later transcribed selectively.

Data Coding and Data Analysis

While data collection processes differ for participant/observation, informal interviewing and focus group discussion, the process for data analysis is similar.[164] The constant comparative method arranges data into evolving categories, generates relationships between them, and develops theoretical constructs. The four stages that Glaser and Strauss (1967) propose are: (a) comparing incidents applicable to each category; (b) integrating categories and their properties; (c) delimiting the theory; (d) writing the theory.[165] *Coding* is the process where the researcher categorises data and explores relationships between the categories. *Open coding* is the first phase during which the qualitative researcher generates concepts or themes that fit the data. *Axial coding* describes a process where data is reconfigured in new ways based on connections drawn between categories formulated in the open coding phase (Strauss & Corbin, 1990, p. 96). It yields core categories for selective coding analysis, where only those themes or categories within the boundaries of the emerging theory are retained. Themes or categories evolve over subsequent codings as the researcher's understanding of the data changes. The coding process is complete when there is theoretical saturation in the theme or category.[166] The third stage sees the ethnographer formulating a theory that captures the worldview of the participants. The final stage is the writing of the ethnography.

Generating Codes and Categories

After the transcription was completed, I reviewed the transcripts of the first focus group and of the debriefing several times. I identified as many themes as I could from the data,

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[164] In coding and analysing participant/observation data and informal interviews it is important that the researcher in ethnographic studies makes good use of field notes rather than relying on memory and general impressions (Newfield et al., 1996, p. 36).

[165] Knodel (1993, p. 45) outlines two essential tasks for the analysis of focus group data: the mechanical work of physically organising and collating data into meaningful segments; and the interpretive process of coding the data and identifying patterns between the coded segments to present substantive results.

[166] Knodel (1993) describes this process as "code-mapping," where the researcher organises material into distinct and relevant segments that can later be examined and interpreted to yield conclusions. Knodel (1993, pp. 46-47) recommends the following steps in the code mapping process: (a) generate an initial set of codes based on the topics covered in the discussion guidelines; (b) create additional codes for issues that arise of special interest; (c) develop nonsubstantive codes to aid analysis and writing up; (d) formulate further codes for analysis within specific topics.

and included verbatim quotations to support each theme. The next step was to combine and condense the themes, recognising that some of the identified themes might represent different stages of a single continuum, which could be subsumed under one theme. I identified seven emergent themes after the revision. For each theme I developed a code and wrote a definition of the code. The coding or categorization is an inductive process that forms the basis of the interpretative analysis. A code is simply a label to mark particular segments of transcript.[167] I developed a code word when I recognized participants expressing a similar thought, feeling or experience that others had used, or when they raised what seemed a significant issue. In this way a code corresponded to an initial theme. The following step was to code the transcript. I attached the code to the segment of the verbatim to facilitate retrieval if necessary. After completing the coding I re-examined the uncoded data to assess whether there were any other themes contained therein that I might have overlooked. I disregarded data that was clearly not relevant to the research question or otherwise unimportant. Subsequently I recoded the transcript with the final set of codes. During this process I also kept notes on ideas for methodology, for analysis and for interpretation, particularly following helpful conversations.

Having developed a template of identified themes, I applied it to the transcript of the second focus group, using the codes already developed. I repeated the process of re-evaluating uncoded data for any new themes. I noted the ways in which the data from the second focus group interacted significantly with the identified themes, by way of reinforcement, change in emphasis, or contradiction. Some new themes emerged. The final stage was to review and code the field work data, using the codes developed from the two focus groups. I repeated the process of exploring uncoded data for emerging themes.

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[167] Morgan (1997, p. 60) identifies three fundamental coding methods for focus groups: (a) all references to a particular code, (b) whether each participant has mentioned the given code, or (c) whether each focus group has discussed the code.

Analysis

Analysis is the most challenging step in the research process. Analysis essentially involves identifying patterns. Field work and focus group data require significant subjective judgment in analysis and interpretation. For this reason it was important for me to be aware of my personal bias in analysing data, and to be open to multiple realities (Krueger & Casey, 2000, p. 140). The nature and the extent of the analysis depend on the research purpose as well as the time availability and the skill of the researcher. The focus of the analysis was on identifying correlations between focus group[168] and field work data. I have used verbatim quotations from the focus group participants and relevant field notes to illustrate identified themes within the particular categories. The final stage involves interpreting the themes. Krueger (2000) describes this methodology as *the interpretive model.*[169]

Reporting

In writing the description of findings section, I sought to balance direct quotations of participants with summaries of their discussion. Morgan (1997, p. 64) writes of the tension between the richness of the data and the distance of the reader from the data source. Qualitative research aims to reduce this distance. It was important in this section to cover thoroughly each theme, and the respective subthemes. I supported descriptions of the themes and subthemes with verbatim quotations from the participants. I weighted the themes and subthemes according to their respective number of lines of transcript and presented them in descending order of significance.

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[168] Researchers place greater emphasis on those topics that recur in different groups, that different participants within a single group raise, and that generate emotive energy. "Group-to-group validation" describes topics for which all three criteria hold (Morgan, 1997, p. 63). Morgan advocates attending closely to nonverbal aspects of group interaction.

[169] Other report models he identifies are *the raw data model* that simply includes all participants' responses under each research question without any analysis, and *the descriptive model* that describes briefly the identified themes and includes illustrative verbatim quotations (Krueger, 2000).

Reliability and Validity

The traditional yardsticks for research methodology of reliability and validity have limited applicability to qualitative research. Moon et al. (1990; cited in Newfield et al., 1996, p. 45) propose alternative criteria which include: identification of researcher bias; sampling techniques geared towards generalization to theory, rather than to populations; and data source triangulation. The ethnographer's role includes interpreting the data rather than simply recording it.

A research team enhances the reliability of focus group data analysis as researchers can compare their independent findings based on the same data. In this study, it was helpful to discuss my findings with the assistant moderator. Having a second and third focus group enabled me to assess the reliability of data across sessions.[170]

The measure of validity is the extent to which the themes or categories are an accurate representation of the participants' perspectives. Descriptive validity refers to the accuracy and completeness of the data; interpretive validity refers to the project's reflection of participants' perspective rather than the researcher's; theoretical validity refers to the researchers' accommodation of contradictory evidence and alternative explanations (Maxwell, 1996). In this project I sought for descriptive validity by recording and transcribing focus group discussions and the debriefing sessions. During informal interviews I took notes and transcribed them afterwards. After Faith and Light meetings I spent time recording my reflections. I strove for interpretive validity by asking questions and seeking clarification during informal interviews and at the focus group. Conducting subsequent focus groups provided an opportunity to check with the group as to whether I had understood them correctly and to seek further clarification in ambiguous areas. I sought to support identified themes with direct quotations. To achieve theoretical validity I have recorded any instances where the evidence has contradicted the identified themes.

[170] The use of the same moderator across focus groups enhances data reliability (Albrecht et al., 1993, p. 62)

Summary

My purpose was to explore the experiential world of a group of parents in a local Faith and Light community. I was seeking answers to a question, rather than testing an hypothesis. It was a *discovery-oriented* inquiry, with a focus on process and meaning. Therefore qualitative methodology was a suitable fit. I selected ethnography as a type of qualitative methodology because I was interested in the *insider's* experience (the parents' experience), and particularly their conceptual models. Participant observation, informal interviews and focus group discussions were the ethnographic techniques I used.

This chapter completes the laying of the foundations for the research project. It is now possible to explore the findings that the ethnographic research tools yielded, teasing out seven recurrent themes that the research data yielded.

Chapter Six

DESCRIPTION OF FINDINGS[171]

Introduction

The focus group discussion developed a life of its own across the two groups. I had circulated copies of the proposed questions to participants prior to the first focus group. While the questioning route I developed differed in format from the questions originally proposed in the information letter, the substance of the inquiry remained the same. While I had decided it was probably important to allow the group to engage informally with one another at the outset to allow comfort levels to increase and trust to build, I reiterated the focus of the discussion during the introduction (see Appendix G).[172] I had made clear that I wished to explore the launching or transition phase of the family life cycle, and the role of Faith and Light in the lives of their families. As the life of the group evolved, it seemed to be more important to allow time and space for the group to move in the direction it wished. I therefore adopted a less directive approach than I had planned.

I have chosen to present the findings under the seven themes that I identified across the two groups. A summary of the themes appears in Table 3. Weighting identified themes in a qualitative study remains at best an arbitrary exercise. Nonetheless, I believe it is important to make some attempt to indicate to the reader the relative importance of each theme in the group's discussions.

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[171] In this chapter I have included verbatim comments and stories of parents. Footnotes contain any elaboration I have deemed necessary on particular passages or the research process. To simplify the presentation I have reserved general discussion of the findings for the following chapter.

[172] After a period of open discussion during which one couple spoke of fund-raising activities they were involved with, one parent explained her need to leave early, and two couples shared stories about their family members and incidents over Christmas, I explained the focus of the inquiry (1.2.16-1.3.17). "I would like to explore your experiences, your thoughts and feelings on being a parent, particularly at the launching phase (when your child is approaching the 'leaving home' age). I am interested especially in the influence of Faith and Light on your family life."

Table 3

Summary of Themes and Subthemes Arising from Focus Group Data

Themes and subthemes	Instances in transcript by line[a]	Instances in transcript by reference[b]
Particular challenges		
Abuse of offspring	160	17
Advocating	132	16
Losing offspring	89	5
Dealing with other losses	88	2
Others' reactions	80	7
Subtotal	*549*	*56*
Other caregivers		
Degree of confidence in other caregivers	168	22
Health care professionals	150	15
Staffing changes	77	9
Subtotal	*395*	*46*
Faith and Light		
Parents		
Mutual support and understanding	77	13
Interaction	73	3
Welcome	23	2
Friendship	21	3
Offspring		
Revealing beauty and giftedness	67	8
Growth and friendship	25	3
Christian formation	16	1
Listening and acceptance	14	4
Suggestions for improvement	94	12
Subtotal	*385*	*49*
Responses to transitions		
Continuing ties	120	11
Leaving home	68	6
Leaving school	52	3
Letting go	40	6
Subtotal	*280*	*26*
Stories from earlier years		
Subtotal	*230*	*16*
Devotion to offspring		
Subtotal	*167*	*24*
Lessons learned		
Attunement to offspring	122	14
Patience	31	5
Subtotal	*153*	*19*

[a] Number of lines of text in focus group transcripts associated with the theme or subtheme. [b] Number of times a focus group member referred to the theme or subtheme.

I first sought to weight the themes according to the number of times each member of the group referred to the particular theme. Where a single statement could be classified under two or more themes I recorded a mark under each theme. It seemed that this method did not give an accurate reflection of the significance of each theme, because it did not distinguish between themes addressed in one line of text, and themes that drew more lengthy comment. In both instances, assuming there was only one theme raised, I would record a single mark under the relevant category. Therefore I opted to weight the themes according to the number of lines of text associated with a particular theme. While this method probably gives a fairer reflection of the amount of time spent discussing each theme, it does not indicate how many of the group members contributed to the discussion. The weighting remains an approximation. Where a passage in the transcript could be classified under more than one theme, I allocated the figure for the number of lines in the passage to the most relevant theme. It meant in some situations, dividing passages into a number of sections and allocating particular lines of the passage to particular themes. I chose to allocate the lines to the most *specific* theme. For example, where parents spoke of instances of abuse in their offspring's childhood, they raised the themes of "Stories from earlier years," "Particular challenges – abuse of offspring," and possibly, "Degree of confidence in other caregivers." In these instances I chose to assign the relevant lines to the more specific theme ("Abuse of offspring") before the more general ("Stories from earlier years").

Based on a weighting by lines of transcript, I have presented the themes in order of importance. Within each theme, the subthemes appear in descending order of significance based on the line count. Uppermost for parents appeared to be the particular challenges they have faced, face and will face in caring for their offspring, whether or not they remain in the family home. It was abuse and the threat of abuse, be it physical, emotional, sexual, or other, that appeared to weigh most heavily on parents' hearts and minds. The demand of advocating for their daughters and sons was the next challenge that parents identified. Others' care for their offspring was the second theme that emerged from the groups. Amongst these issues, it was parents' ambivalence around caregivers, and their experiences with health care professionals that dominated. The third theme in the

discussion was Faith and Light, parents emphasising the mutual support and the interaction they experienced, and the manner in which the community revealed the beauty and giftedness of their offspring. Dealing with transition was the fourth theme, which received much more attention in the first group than it did in the second (where it was the least mentioned theme). In this domain, it was the issue of continuing ties with their offspring, once offspring had left the family home, which rated most mention. The fifth theme in order of lines of transcript was the childhood stories of their offspring, which parents recounted. This theme probably occupied more time than would appear since, as mentioned previously, I classified some of the stories under other headings, if the other headings provided a more exact fit. Accounts of devotion to their offspring made up the sixth theme in the data. The final theme captured that which parents had received from their offspring, the foremost being a refined awareness of the nature and personality of their offspring. Parents also referred to the patience that they were acquiring through raising their daughters and sons.

I have supplemented the presentation of the findings of the two focus groups with data arising from a third group meeting that participants themselves had initiated, and with field notes from informal interviews I conducted, and from participation/observation in group meetings at a local, national and international level. The dominant issues in the third group meeting related largely to those identified from the first two focus groups, suggesting that data saturation had been reached. Additional issues raised in the third group, appeared to be variations on themes previously identified. It seems that the particular themes identified may find different expression among groups depending on the specific membership of the group, and the particular experiences members have recently encountered. I have identified these additional issues in the presentation of findings. Before moving to an elaboration of the themes, I repeat that I have changed the names and any identifying characteristics, such as names of institutions and locations, of participants. Their demographic information, including the living arrangements for their offspring with an intellectual disability, appeared in Table 2 in the previous chapter. It may be helpful for the reader to recap the names of participants and their offspring: Wendy and Jack (who was present only for the third focus group), and their son Peter,

who resides in the family home; Vicky and her daughter Ursula, who also lives with her mother; Paul and Tina, and their son Henry, who lives in a group home; Hugo and Julie, and their foster daughter Maria, now a core member of a Christian residential community; and Kevin and Frances (who both joined only the third group), and their daughter Cassie, who remains with them at home.

Particular Challenges

I disclosed to participants in the second meeting that the most striking feature for me in moderating the two focus groups was the burdens parents continued to carry, whether their offspring remained with them at home or not (2.38.2-8).[173] The data bore this out, where discussion of various challenges accounted for 549 lines of transcript. The third group meeting confirmed that the particularity of the challenges that parents discussed varied depending upon the composition of the group, and upon what participants were dealing with personally at the time. That being said, it seemed that the challenges raised in the first two focus groups were experiences that resonated with all participants. I have presented the identified challenges in descending order of significance based on lines of transcript devoted to each issue. It will be noted that the first issue concerning abuse was clearly the most pressing (160 lines), while the last three ("Losing Offspring" [89 lines], "Dealing With Other Losses" [88 lines], and "Others' reactions" [80 lines]) occupied similar amounts of the group's time. It is significant to note that the challenges parents face was not an issue that had been raised expressly in any of the local meetings that I had participated in over three and a half years. Nor was this theme or any of the identified subthemes addressed directly at either of the two national meetings or the international meeting at which I was present. I will return to this phenomenon in the subsection "Suggestions for improvement" in the "Faith and Light" section.

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[173] The citations used are references to verbatim transcript from the three focus groups. The first numeral refers to the focus group (first, second or third), the second numeral to the transcript page number, and the third group of numerals to the line references. As noted in the information letter to participants I have substituted pseudonyms for the actual names of participants and have altered the identity of other people, agencies and places referred to. I have sought to be consistent in the use of pseudonyms throughout the paper.

Abuse of Offspring

Abuse and the fear of abuse occurring was a recurrent theme. Wendy gave a detailed description in the first group of physical, emotional and sexual abuse, which Peter suffered while at a private school in his teenage years.

> *Wendy* ... [Peter's teacher] recommended that we send him to a private school, that had a new theory.... And she said, "This might give Peter a big chance, and maybe you should think of sending him over there." Well, we sent him there, but he was abused beyond belief! (1.11.21-27).[174]

> *Wendy* ... My last straw was when a boy took a pair of scissors and pushed it down his back. And Peter didn't even tell us about it, until a couple of days later... I saw him with his shirt off, and I said, "What's wrong with your back!" And then he told me, "The boy did that with scissors," but told him not to tell anybody. Or they'd do something worse. Such horror stories.... And he was sexually molested by another boy in the bathroom. And the last straw was when the scissors happened, and I went in and said, "He's out of here!" So we took him home... (1.12.17-13.1).

The incident remained of such significance for Wendy that she raised it again in the second group (2.49.27-50.8). In her second account it seemed that Wendy felt guilty for not having recognised sooner what was happening (2.47.27-33). Wendy gave a further example of the verbal abuse her son was subjected to, and of how she dealt with Peter's questions around it.

> *Wendy* ...Well, the word "retard" comes up quite a bit...
> *Hugo* Boy, does it ever...
> *Wendy* ... No, that's it... Peter used to come home and say, "What does that mean, 'retard?'" And then you try to explain it... I'd say, "Why? Where did you hear it? What does it mean? Did it (missed word) you?" And... "I don't know. Somebody called me that today." And I said, "Well, 'retard' means kind of

[174] In the quotations from the focus groups I have omitted repeated words and phrases, and fillers such as "um," "ah," "you know." I did not include expressions of approval from others when a participant is speaking. It seemed that their inclusion would not add to the meaning of the quotation and would make them more challenging to read. The words included in the quotations are those of the participants except where I have substituted pseudonyms. In some instances I have replaced pronouns with their antecedents to improve clarity, indicated by square brackets. I have indicated pauses in the speech of the participants through the use of three ellipsis points (...). In some instances I have omitted interjections from other participants or from me in the course of the participant's quoted speech, unless the interjections contributed substantially to the meaning of the quotation. I have used four ellipsis points (....) to indicate any omission between sentences. See *Publication manual of the American Psychological Association* (5th ed.), p. 119 para. 3.38.

> 'slow,' and we all have a bit of that, in some way or another... We're not all good at everything." And so... you try to spare their feelings... (2.50.14-32).

Wendy appeared to see Peter constantly as a victim. "I think this other boy that he was afraid of, would incite the others to hurt him. So he again was a victim..." (2.50.7-8). She described the change that occurred in Peter owing to repeated victimisation.

> *Wendy* ...Because Peter was victimised so much, as a small child, and was afraid and did everything everybody told him, or he thought he was going to get hurt... Then he turned around, and said, "I'd not going to be told anything anymore." He said, "I'm sick and tired of it." And he verbalised it. "I am not going to be told what to do any more." So then he took all the verbs, imperative verbs like "look," "see," "guess," as being command words. So he reacts on all those now. So if you say one of those... I'll say, "Guess what happened...?" He'll say, "What?" And I'll say, "Can you guess what happened?" (Laughter). I put it in the form of a question, and... So if you ask him anything in a question, he does not react and he's great. But if you say something "Do this," in any way, then he reacts... (2.54.26-55.6)

She expressed her distaste at the mere thought of what children with an intellectual disability had suffered.

> *Wendy* ... You think over the years of all the trauma and abuse that these kids have gone through, and if you started thinking about it, it just makes you sick... You try to get it out of your head... If you only knew some things... (2.49.24-27)

Paul appeared to accept that it was inevitable in the school situation that any of their offspring could be assaulted, picked on and made fun of.

> *Paul* ... But all children get assaulted at school at one time or another, at the playground. It's a bad place... The kids are always looking for someone to pick on, and someone who is an easy target. We know that our son came home with words that he did not learn at school. He learned it in the yard, and that stick with him a lot better than what is taught in the classroom... because what happened in the classroom it soon went out the window. And then he had a big smile on his face, then he said he bad word. Yes, he knew... But the kids get fun out of that doing these things, and you cannot protect them day and night... (1.34.23-32).

He repeated these thoughts in the second group, adding that adults as well as children can taunt their offspring (2.50.9-12). Nonetheless he recalled the impact of the sudden realisation that his son Henry could be abused in an institution.

> *Paul* Our son was at Sunnyside for seven years, where they were small, two or three people on the floor. Then he went to Lake Alice for a year and a half, where there were 23 on the floor... And all of a sudden, it came to my mind that there's

> a possibility that he might get abused... Because there are all kinds of people, especially at Lake Alice.... Well, it's a secure place... They're locked up, but I mean, how can someone supervise that 24 hours a day? (2.51.1-10)

Julie recounted with gratitude the intervention of a social worker which prevented Maria from being exposed to likely abuse in an institution.

> *Julie* ... And [social worker Vanessa] knew that if Maria stayed in Cherryfarm, there would not be a Maria |[175]
> *Hugo* She wouldn't survive |
> *Julie* she wouldn't survive with these big adults... So that's how Maria got into Parkhill... (2.51.21-27).

Hugo recognised the inherent difficulty in being able to protect his foster daughter Maria, even where agencies were teaching preventative strategies such as "Circle of Friends."

> *Hugo* ... he called it just a spiral circle, where the child is supposed to learn who to shake hands with, who to hug, and who to stay away from. And that was very, very helpful but it doesn't mean that it has shielded the girl from attacks or anything else... as you say Maria was abused... (1.34.12-16).

The depth of the anxiety that participants with daughters who were nonverbal experienced was evident in the emotional exchange between Julie and Vicky.

> *Julie* Yeah, but how many people take advantage of these children too, that can't speak for themselves. They can't answer any questions... they just can't do nothing. How much abuse is out there right now of these children...?
> *Vicky* Don't, please... don't even say that... I am just so scared...
> *Julie* Well, Vicky, it happens! (2.27.22-29).

Hugo revealed how deeply he was impacted by the abuse of offspring. 'You're lost... you carry the whole burden...' (2.38.21).

It was a theme that found expression in the third group meeting. Jack (husband of Wendy and present for the first time at the third meeting) recounted an incident at school where there had been inadequate supervision of 12 children with an intellectual disability, who were being verbally and physically abused (3.16.28-3.17.13). His impression was that the school did not want to take any responsibility for the children. The experience had stayed with Jack, evidenced in his response to Frances' remark.

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[175] I have used a vertical line (|) to indicate that the participant speaking was interrupted by another.

Frances... But things have come a long way since then...
Jack ... But these things stick with you... (3.18.6).

It was significant that the issue of abuse was neither raised nor addressed directly at local, national or international meetings. At a local meeting in February one participant referred to a painful episode she was living as a parent of a child who had been abused. She articulated her frustration over her perception that professionals in various agencies seemed to be avoiding the issue.

Advocating

Whether or not their offspring remained in the family or not, participants agreed that they had no choice but to advocate for them (132 lines).

Julie ... and I've been talking to somebody now, and they've advised me to get a parent group to speak up for these kids who can't talk for themselves...
T So, in many ways your role as parents is to be advocate for your kids? [176]
Wendy You have to...
T You have to |
Paul | You have no choice... you have no choice... (2.26.13-24).

Wendy expressed concern over who would fulfil that role when Peter was no longer living with them. "... and then when you pass them off to someone else, you have to hope that there is an advocate there for them, as long as they're with someone else..." (2.26.26-28). Participants whose offspring were nonverbal perceived an even greater need for promoting the rights of their prodigy. Vicky emphasised that Ursula is able to "understand a lot, but she can't say what she means" (1.24.30-31). In the second group, Vicky expressed her anger at not being told about a vehicle accident on the way to school in which Ursula had been involved.

Vicky ... Imagine how we feel... Then they say, "We think she's OK" |
Julie Because these kids cannot say anything for themselves...
Wendy ... That's right... (2.26.4-9).

These parents also wondered about advocacy after their offspring left home.

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[176] I have used the letter "T" to indicate when I, the researcher, am speaking.

> *Vicky* … and if I see bruises on her, it scares me, "Who's done it, or what happened?" But she cannot tell me |
> *Julie* We are also Mum and Dad, but because Ursula and Maria, they cannot talk, they cannot think for themselves, we also have to be their advocates, we have to talk because they can't, for them. And yes, they move on to an institution or a group home, those people are there paid to look after them. It's not the same…
> *Vicky* You're right… (1.33.16-25).

In the third group meeting, parents whose offspring were non-verbal were keen to identify the added challenges they faced, particularly with regard to sexual abuse. Their offspring were able to articulate neither their fears nor their needs. They were not able to describe what had happened (3.2.22-3.3.2; 3.3.24-26; 3.6.8-17; 3.38.23-31).

Advocacy battles had been waged on a number of fronts. Hugo and Julie had fought to have a school for people with disabilities remain open.

> *Hugo* … When they decided to close the school in Bedford, we fought. Because the only reason, they were moving the handicapped out of there, because they wanted to make it a French Immersion school… And the excuse they give was, "Well, the building is air-conditioned." (Chuckles). Well, oh boy, you think we didn't end up in City Hall, and going in front of the school board and all that? (2.36.28-37.2).

After Maria was burned when someone spilled hot coffee on her, they lobbied for a policy to prevent caregivers from carrying coffee at certain times.

> *Julie* … And then we complained, because when we took Maria to school in the morning they were taking the kids off the transit buses and every one of them had a cup of hot coffee in their hand… these school teachers |
> *Hugo* They were helping the kids off the bus with one hand, and drinking their coffee |
> *Julie* So we made a stink about that, and we said, "This has to stop." So then, they made the rule, "Nobody walking around anymore," and "Nobody comes in there and goes in and helps themselves to a cup of coffee…" (2.25.14-25).

Hugo and Julie's current pitch is to have parents represented on the boards of group homes.

> *Julie* And that's what we're fighting for now, in Social Services. We've been there and they agree with us, that we have to start having parents on boards… (1.58.1-3).

Hugo believes that their stance has left them unpopular with agencies around the city. "We're hated by a lot of people in Bedford, because we fought" (2.35.6-7).

Vicky described the struggles she has experienced in air travel with Ursula. (2.3.22-2.4.5; 2.6.16-25). "...there's all kinds of complications... there all kinds of things coming up, that with a handicapped person to go any place [*sic*]" (2.4.15-17).

> *Vicky* And they were going to separate us again. And I said, "Well, she needs me, I have to have a seat next to her." So they took her straight in the back, to the very last seat. But we weren't the only one[s], and there were people [who] were very, very upset... (2.6.20-23).

Participants returned to this theme in the third group meeting (3.5.24-31).

> T So as parents, you really have to be advocates for your kids. I mean you've got no real choice other than this...
> *Julie* I feel whether they can speak or not, you still have to be there for them...
> *Hugo* ... and never give up, never give up... You're bucking all kinds of things, and just keep harping, keep on harping... They'll eventually have to do something, because you become such a nuisance, that to get rid of you... sign anything you push... (3.7.9-18).

Other participants concurred. Jack described his experience. "You have to be a nuisance to get anywhere..." (3.8.2). Julie and Frances chimed in.

> *Julie* ... You have to fight, you have to fight, and you can't give up...
> *Frances*... They've got so many things on their plate, that they... the ones that do, are troublemakers come to the surface, so to get rid of us, they'll do... (laughs). You have to be a troublemaker, a troublemaker... (3.8.9-15).

The need for parents to advocate was not apparent from participant observation in local meetings, nor was it raised in the informal interviews conducted. One exception was a phone conversation with a parent from another Faith and Light community who was struggling with government agencies to secure residential options for adolescents with an intellectual disability, for whom living with their own families was no longer a viable option. It was clear that she accepted that advocacy was necessary as a parent of a child with an intellectual disability.

Losing Offspring

Another scenario that evoked considerable anxiety in the participants was discovering that their offspring were missing. Wendy described what she went through when Peter and she missed each other in the subway system as she was teaching him how to take public transport to a new school. "Yes, it was so scary.... And my heart was just pounding, my head was just pounding" (1.13.11, 22-23). Paul recalled two incidents where they had lost Henry: when they were planting trees together, and Henry had wandered off; and when dogs had scared Henry as he was riding his bike (1.15.20-16.14).

Wendy risked disclosing her recurrent dreams of Peter being lost and not being able to find him (1.16.21-23). Vicky described her similar experience where on waking after a similar dream, "Right away, I go and see if [Ursula] is OK" (1.17.17). Julie recounted that even after Maria had left the family home, "... I hear her calling, and I'll wake up, because I think she's in the next bedroom" (1.18.1-2). For Julie, this bolstered her conviction that Maria remained bonded to them. "Oh yeah... she's still mine, she's still part of us" (1.18.8).

Dealing With Other Losses

Paul and Tina referred in the first group to the death of another son 11 years ago. Paul agreed that they had had their share of heartache, and added that "the hassle isn't over yet" (1.7.5-9). Vicky gave an account of her husband's prolonged illness over 7 ½ years following surgery (2.15.24-20.3). She struggled with all the responsibilities she carried in caring for both her spouse and Ursula.

> *Vicky* ... I had to work. [My husband's] pension was very little. And I was working. I went out house cleaning, because I couldn't get a job, where I was there at certain time. I had to get Ursula ready in the morning, send her off, go to work... have to be home when she got home. I had to look after the garden, the washing, the cooking and living it..." (2.16.15-20).

She found his death particularly difficult.

> *Vicky* I tell you, when my husband died, I thought I was going to have a nervous

> breakdown, because everything was going up. At night time I couldn't sleep either, I was going nuts. My brain was going… [Vicky makes a sound].
> *Paul* … [It was] more than you can handle |
> *Vicky* It was just a horrible feeling… and my mind just didn't work…' (2.17.20-28).

It appeared that the isolation that Vicky felt was one of the greatest challenges.

> *Wendy* … and you had no family here to help you |
> *Vicky* nobody to turn to…' (2.17.6-8).
> *Vicky* … It's been hard being alone… (2.19.22-23).

Others' Reactions

As one might expect, participants reported considerable variation in how others responded to their offspring. There were different experiences of how clergy and members of their respective faith communities treated their prodigy. Vicky revealed her pain and anger. "…We have a priest that wouldn't touch Ursula, like she has a disease or something…" (1.46.3). Paul described how invasive it could be for Henry if others in church stared at him. "…that turns them off, because they cannot maintain steady eye contact" (1.46.31-32). Hugo and Julie remarked on the response of fellow parishioners although it was difficult to gauge how they perceived the reaction

> *Julie* It's surprising how people in the church also react to these… people. Many, many years ago I think these children were just |
> *Hugo* Exorcised |
> *Julie* I hate to say it, but cast off |
> *Hugo* kept hidden, locked up… (1.43.5-13).

Hugo and Julie reported a more affirming response from their parish priest (if not from the congregation).

> *Julie* … When we took Maria, we had a talk with the Father of our church, and he was all for it, and I can remember we took her to midnight mass once, and as he came up the aisle to go up to the altar with the baby Jesus… it was a Midnight Mass, he blessed Maria |
> *Hugo* with the baby Jesus |

> *Julie* and we talked to him about making noises in the church, and he told us that she was more welcome in the church than other people. [If] they didn't like it, the noise, they could stay at home…' (1.45.22-24).[177]

In the second group, Vicky articulated the ambivalence of responses from the general public.

> *Vicky* It all depends on how people ask about them. Because some people are very sympathetic and caring, but there are some people look at them.... Some people are very nice, and even children, some are very nice. Some are so cruel… (2.9.19-25).

She gave an example of how she dealt with the derision of a young boy.

> *Vicky* I can remember an experience. We'd been living in this house, and there was a little boy… I always take Ursula for walks.... And there was a little boy who used to come, and… all kinds of questions asking, "Why doesn't she talk? Why you have to hold her hand? Why she walk like that?" And so I was kind. And I told him that she had problem. When she born, she was sick. And all of a sudden he turned like a nut… He started [Vicky imitates noises the boy made] doing all kinds of crazy things. And I said, "Now why did you do that?" He said, "I don't know…" And I said, "You don't have to do that to her." And Ursula thought it was funny, so she started laughing. And he said, "Well, she's laughing." And I said, "Well, I don't think it's laughing matter. How would you like it, if you're like Ursula and we do that to you?" He stopped and think [*sic*]. And next time again. And he kept coming, and then quite a few times he would make all kinds of stupid faces. So I said to him, "I was nice to you, I talked to you nicely… and if you can't be nice, please don't come around any more." And then he still came, and I said, "I'm going to kick your bottom, if you don't disappear." He never came around again (2.9.29-10.17).

While Vicky was aware of the adverse responses of other children at school, she maintained that having their offspring together with other children could benefit children without disabilities.

> *Vicky* … and I thought when they were blending in handicapped kids in the schools, in a way it was… I felt sorry for our kids, the handicapped kids… because I know that the children can be cruel… But then I thought that it's a good education for them to see that they're people too, because some of the children are like that… (2.10.26-11.1).

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[177] In the third meeting, Julie and Hugo repeated their experience of how accepted Maria was in their subdivision and in their church (3.15.2-22). "But I was surprised that she was so well accepted in our community…" (3.15.21-22). They balanced this impression with an account of a critical response they received concerning Maria's behaviour in a store (3.15.26-3.16.7).

Jack described, in the third group meeting, the adverse response from some neighbours to the opening of a residential Christian community for people with an intellectual disability (3.10.8-3.11.12). Later he added, "But any of these homes that are set up for handicapped, you get all kinds of flack..." (3.12.10-11). Other parents gave voice to their experience of ostracism and exclusion. After listening to accounts of dismissive responses from neighbours, I asked participants if they had grown used to dealing with criticism and the social stigma placed upon them (3.13.12-13). A number of participants contributed.

> *Jack* No, never...
> *Frances* No |
> T I mean I don't think I would, but I just wondered if you've been dealing with this for twenty, thirty, forty years |
> *Paul* You accept it |
> *Jack* You get so used to being excluded from certain things that you take it as a natural, you know... (3.13.15-25).

In the same group meeting, Wendy described her anticipatory anxiety over others' potential response to Peter when going somewhere with him.

> *Wendy* There's always that apprehension before you go some place... How is the situation going to be? Will the people accept? How are they going to act? That's the thing. It makes you nervous. It... (3.16.23-26).

Access to resources

Wendy's husband Jack, who joined the third discussion group, reiterated the challenge parents faced in discovering relevant information and resources for their offspring. While this challenge had been implied in the two previous focus groups, particularly in relation to abuse, it was Jack who articulated it most clearly in the third meeting.

> *Jack* ... that's the problem with a handicapped child is that no one knows where to look to find the information that they really need... You know, there's all kinds of people out there wandering around... (Sounds of agreement). And everybody finds out a little bit, little bit, little bit... (3.1.6-10).

Later in the group Jack identified the need he perceived for coordination of the various resources available to parents.

> *Jack* I think you can see, it's almost a fractured type of care... Word of mouth, rather than any co-ordinated effort... I said what you need is one manager, that

> gets everybody together and you can send them to wherever you want... (3.37.25-28).
> *Jack* It's a ridiculous infrastructure... You should be able to phone one area, explain what it is you need, get the help right there without a referral... (3.38.2-4).

Hugo concurred in describing the response of a Federal politician to his questioning.

> *Hugo* But, he's an MP, and I thought that he was well-versed, but he says... There are a few things that I know, but he says, there's a whole pile I don't know... And he said, I'm with Federal... I couldn't help you on that side at all, with anybody (3.5.31-3.6.6).

Participants articulated their need for information as parents (3.1.17-20). Jack was critical of the *amount* of information that caregivers reported, making it difficult to understand (3.26.30-3.27.2). "... Pete gets to go out with a worker for two hours, we'll say... Come back in, she spends half an hour writing up a thesis..." (3.27.8-10). Paul, on the other hand, appeared to appreciate receiving the monthly assessments of Henry.

Parents made reference to resources available to them, and resources that they thought might help them. One of the last topics that the group discussed in the third meeting was access to resources such as home care and assistive devices through various agencies in the city (3.36.27-3.37.23). Hugo reflected on the importance of other parents' empathy as a resource, whether those parents had children with disabilities or not.

> *Hugo* ... But by the same token if you could recruit other parents, they don't have to have handicap [handicapped children], but if you could convince them of what your needs are, because of the handicap, you're home free... You get two thirds of your problem solved... (3.10.2-6)

It seemed that the participants found considerable common ground in the challenges they had experienced and continued to experience in parenting their offspring. The spectre of abuse of both sons and daughters cast a long shadow, and unfortunately the fears of parents were well-founded as personal stories attested. While some seemed more comfortable in their role of advocacy than others, participants agreed that in their experience advocacy was a nonnegotiable part of the parenting package. Parents recounted their concerns around losing their offspring. It was obvious that other losses in the family's life impacted considerably on the parenting challenges they already faced.

Parents depicted the variety of responses to their offspring from young and old alike. It was in the third meeting that participants discussed resources and their access to them. The challenges that parents faced appeared to accentuate their role as caregivers of their offspring. This may have been one reason why some participants expressed deep ambivalence over the ability of others to care for their offspring, which was the second theme to emerge from the data (395 lines).

Other Caregivers

Some of the participants expressed a lack of confidence in the care that their offspring received in day care centres, in workshops, and in group homes. They shared stories of frustration and disappointment. These were offset to a degree by some affirming accounts. This was the first subtheme in this category, which accounted for 168 lines of transcript. Participants gave mixed reports of their dealings with a variety of health care professionals, the second subtheme (150 lines). Here it was more evident that some professionals exercised a high standard of care, for which parents expressed respect and gratitude. Finally, the third subtheme to emerge was the impact of change in care-giving personnel on offspring (77 lines). Participants reported that it was challenging and often upsetting for their daughters and sons. An observation arising from field note data taken at local Faith and Light meetings was that three of the parents had opportunity to interact with caregivers for their offspring in a context outside the group home or other residential setting. None of the participants referred to this phenomenon, so it is not possible to conclude whether the experience of mingling with some support workers in the presence of their offspring in an environment separate from the group home and the family home was helpful for participants or not.

Degree of Confidence in Other Caregivers

Julie expressed sentiments shared by some participants.

> *Julie* There's a feeling in parents that no matter where that child goes, when he leaves home, or he's not like your biological kid that can fend for themselves, you

> feel that no matter where that child goes, nobody can do for that child as the parents do (1.19.26-29).

She maintained that a paid caregiver would not provide the same standard of care that a parent would (1.33.19-23). She reiterated her belief, in the third group meeting, that "nobody can take care of your child as good as you can" (3.22.26-27). Yet she manifested some ambivalence as a subsequent remark attested. "... I know that other people can do for her just as well as we can, but it's hard to understand that, and to accept it" (1.32.21-22). An incident involving hot coffee being spilled on Maria at a day care centre may have fuelled her suspicion.

> *Julie* Nobody told us. We went to pick her up after school and they said, "Oh, Maria's chest is a little red from this girl dropped coffee on it." We took the top off that Ursula had... It was stuck to her. Ursula had great big blisters, she had... We had to take her to the doctor and they had to put burn... give us burn ointment....
> *Wendy* Did they leave her all day with this burn?
> *Julie* Yeah... They said they checked it and it was just red. By the time we picked her up after school there was [*sic*] great big blisters... (2.25.5-30).

Vicky claimed that her concerns about the adequacy of care Ursula received were based upon her experience. "... And then lots of time[s], things happening [*sic*] that it proves that nobody does care as much as they should..." (1.19.31-32). She recounted in the third group meeting how Ursula had fallen in a bathtub when being cared for by others (3.40.27-3.41.11). Adequacy of care seemed to include the manner in which support workers related to Ursula. Vicky indicated how sensitive Ursula was to the tone that caregivers used with her. "...but she doesn't like to be ordered" (1.36.1). Wendy agreed with her observations.

> *Vicky* ... this lady [support worker] coming giving her shower, she just ... this, this, this, that (motioning with her hand)... I said, "Hey, OK, sergeant-major, can you speak a little gentler?"
> *Wendy* That's right, good for you |
> *Vicky* You can get a lot more from Ursula if you speak to her gently... But [the support worker] feels that she's same age [*sic*] as Ursula and because she is looking after her... She thinks she is high and mighty... And we don't have that much choice do we...?
> *Wendy* ... The voice |
> *Vicky* It makes so much difference |
> *Wendy* How something is said... (1.36.11-30).

Caregivers' failure to notify parents of mishaps and possible harm to their offspring appeared to undermine Vicky's confidence in the adequacy of care provided. She described her response on discovering that the van, which collected Ursula had been involved in an accident. Parents had not been informed initially.

> *Vicky* ... And I didn't find out until last Tuesday that their van was in an accident a week ago last Saturday... And I was thinking back and Ursula wasn't well on Sunday and... She kept putting her hand on her head |
> *Wendy* Oh, she was in that van?
> *Vicky* Yes...
> *Wendy* ... They can't tell us these things...
> *Vicky* ... They cannot... that's what I said to him. I said, "Why, why wasn't I told about it?" About a year ago or so, they were in an accident again, and they say that everybody was fine... Ursula. They changed the van that Ursula was in, went to the shop, and I was told... I think [the director of day care centre] wrote that they had an accident, and so they had to change van and it was late getting in... And Ursula had showed me her knees when she came home and I look at her knees were all bruised up [*sic*], and... They said nobody was hurt... Ursula couldn't walk for three days... (2.23.15-24.2)
> *Vicky* ... and I was really surprised nobody notified me... I didn't know... Then in my mind, I kept going back to what was Ursula doing and how sick was she... is sick because of the accident... (2.24.28-31).

Tina empathised with Vicky's situation and suggested advocating for the implementation of safeguards.

> *Tina* But, I think really something should be done about if there is an accident, that the parents should be told... I cannot get this rule that should come about [sic]... (2.28.10-12).

Vicky reiterated the depth of her anxiety that there would not be others who would know when Ursula needed attention if she herself were not there.

> *Vicky* It scares me to death, if Ursula... if something happen... and I'm not around. Would anybody notice that she's in pain or anybody? There were several times that she has fallen... But nobody saw it, nobody know [*sic*]... (2.27.17-20).

She expressed concern about the possible consequences for their offspring of workers' inattention at day care centres.

> *Vicky* ... Ursula was supposed to be picked up by [a taxi company], and they sent away [the taxi] because, they said Ursula is out. ... Nobody knew she was there. Anything can happen... She could have been raped... or done anything to

> her [*sic*]... Nobody even knew she was there... (2.28.26-30).

Given the many disappointments, it was reassuring to hear Vicky acknowledge that one support worker had invited both Vicky and Ursula to join her family for a trip to Florida, which proved to be a positive experience (2.3.14-20).

Wendy's account of Peter's time in a group home revealed her dissatisfaction with the care provided.

> *Wendy* ... [the support worker] would come in for their nightly meal, and then they would leave. And then, if they needed help with their budget or anything, there was someone there from say like 4pm to 6pm, so they would look after maybe some shopping and budgeting... But the three men were pretty well left on their own.... They didn't know each other, they had nothing in common. And the idea of this is as independent supported living, so they expected the people living there if they ran short of food to take money from the petty cash and go to the store. So many times when we went there to take him back after a weekend, there was no milk in the fridge, there was hardly any food, and he was trying to cope in the situation, which he was not really able to... (1.39.9-23)
> *Wendy* ... [Peter] was not able to cope with that situation... It wasn't safe... (1.41.5-9)
> *Wendy* ... and I mean we had him every weekend, almost every weekend because we didn't like what we were seeing (1.41.29-31).

Hugo gave an account of the conditions in one of the institutions in which Maria had lived prior to coming to them. It did little to allay participants' concerns about the adequacy of care beyond their own homes.

> *Hugo* There were 22 in that ward where she was, 22 girls, and there were 5 people to look after the 22... Most of them, hardly ever kept their clothes on... Quite a few of them never signalled or anything to get to the bathroom, so it was all over the place. The three people that were on the day, dayshift, of course had to do all that clean-up and so on. They had a half an hour to feed them lunch... They used to take the plate and then put the dessert on top of it... And they had like a strait-jacket, they would lock them up in there, sit them at the table, and they would spoon feed... That's what they could because they had half an hour to feed 22 of them |
> *Julie* That's why Maria is a dessert fiend, because they would serve meat, potatoes and vegetables and then the dessert was thrown on top |
> *Hugo* The dessert would hit the palate first of all... But, the one lady that was there, had the same name as one of our social workers... and she said, she was appalled at the condition when she got the job, in there... (2.51.30-52.15).

Staff had difficulty in believing the change in Maria after spending a year with Julie and

Hugo. "We took Maria back for a visit a year later… They're all… couldn't believe that this was Maria…" (2.53.6-7).

While significantly outweighed by the dissatisfaction participants reported, it is important to document some participants' satisfaction with the standard of caregiving. Paul and Tina appeared content with the care and support Henry was receiving in the group home. They remarked on the manner in which staff consulted one another and kept comprehensive records.

> *Tina* … I wanted to say that in a group home where our son is now though, they always made all the caregivers… They discuss how they can handle these |
> *Paul* The pros and cons |
> *Tina* situations, so they learn a lot from each other… the caregivers themselves
> *Paul* and they keep records… Everything is on paper… The next one comes in and just look at the paper and know already. If he phone and say, "OK… Well, that is what he did this morning, that is how the day has gone…" (1.37.3-18).

They were the only participants who recognised the burden that some support workers carry in caring for offspring outside the family home. Paul seemed to invite participants to look at caregiving from another's perspective

> *Paul* … We also know about some people that take their job that is serious |
> *Tina* How so? |
> *Paul* and instead of solving problems they got their own problems and they get weighed down… And they have to quit their job… So the shoe is not always on the one foot… Maybe on the other foot too… (2.28.1-8).

Health Care Professionals

While there were disappointments, participants on the whole appeared to have had more favourable experiences with health care professionals than with support workers. Sometimes it required time and energy to locate competent and understanding professionals. It appeared that parents considered the effort well worth it, where their quest was successful.

Julie and Hugo's family doctor agreed to take Maria as a patient. Julie spoke with pride of his being awarded the "Dr. Carson award for looking after handicapped [*sic*]" (1.46.30-47.5). They described the growing trust between their dentist and Maria.

> *Julie* When we first took Maria, the dentist would sit Hugo in the chair, and put Maria on his lap, and he used to put his arms around her and hold her... But she has always gone to him. And he said he has less trouble with her than he does for a normal child... (2.54.5-8).

Vicky recalled how helpful a paediatrician at an institution had been. "... He took Ursula in as a private patient too... He was from Lithuania also... And it was helpful for me because my English wasn't very much..." (2.12.11-14). Participants shared positive experiences of times their offspring were in hospital. Julie reflected, "But [Maria] was treated good... She had a good surgeon, and good nurses..." (2.56.21-22). Wendy remarked that staff's knowing the best way to communicate with Peter probably helped his time in hospital.

> *Wendy* ...So now when we go to the dentist, or anything, I write this all out. I say, "If you want cooperation from Peter, and you'll get great cooperation, ask him to do something, don't tell him..." And that's it... *That's it* [italics added]... And I did that when he had surgery on the veins. He had veins stripped... I sent that note to... They treated him like a king. He didn't want to leave the hospital, because they were so nice to him. But they had to have that knowledge that I have, in order to deal with him. And you'll have no trouble with Peter, if you ask him... (2.55.6-14).

Several of the participants mentioned by name a counsellor who was part of a local team, which specialised in working with families with children with a disability. He informed Vicky about Faith and Light and put her in touch with Wendy knowing that Wendy was a member.

> *Wendy* ... He could see that you were ready for some affiliation with other people...
> *Vicky* ... He was a very nice person... He told me that I'm a very nice lady (2.20.21-32).

Apart from his personal qualities, Wendy appreciated the counsellor's interest in them as parents, which was rare in her experience amongst health care professionals. (See also 1.38.13-15).

> *Wendy* … He's a wonderful guy |
> *Hugo* Terrific |
> *Wendy* Oh, he's a wonderful man….
> *Hugo* He has a special touch that you don't find in all of these service people |
> *Wendy* and he deals more with the parents than… So I mean he's part of that team… His role is to help the parents, which you don't find very often… Usually you find people to help the ones that have the problem, but the parents have the problem too... (2.21.22-22.4).

At the same time Wendy referred to a situation where she perceived that one of the team members with which the counsellor worked had coerced Peter into making a decision to move out of the family home, when he was undergoing a period of depression.

> *Wendy* … So they counselled us, and got to know Pete quite well, and would take him out. And they kind of coerced him into saying that he might go to another residence… And they didn't really… I don't think they introduced him to the people he was going to be living with… They just assigned him a spot in a house… It was a group… well they called it a group home, but it was three men living together… (1.38.25-39.4).

Participants recounted several episodes with health care professionals, which had left them upset and angry. Hugo and Julie expressed frustration over the apparent inadequacy of formation of professionals working with people with an intellectual disability.

> *Julie* … But, do you know what I found out last year? That doctors never had a course in the medical school on handicapped until last year. And it's in the medical courses now that doctors have to look and take a course in handicaps |
> *Hugo* Even the programme in the teachers' training was never included until thirty years ago. In 1970, somebody all of a sudden said, "Whoa…" (1.46.16-23).

Vicky alluded to significant variation in doctors' manner with Ursula (1.46.25-28). She recalled her distress at how Ursula was treated in hospital when she had eye surgery as an infant.

> *Vicky* … Then they done [*sic*] the surgery in both eyes… after she was taken up. And it was very terrifying for us too, because when they got her out of surgery, both of her eyes were covered up. And we were not allowed to touch her… For she was in that cage like a monkey… And she screamed and tried to reach out… (sounds of sympathy in group). And we were not allowed to be with her, and we had to leave her there… (2.13.19-25).

Participants seemed to be particularly attentive to professionals' way of interacting with their offspring. Wendy found the approach of one dentist offensive, and she did not take Peter back to him.

> *Wendy* ...I can remember taking Pete to a dentist, and we always researched to say, "Who would be good with children?" And we thought this was a good children's dentist, where at least it was recommended that he was a pretty nice fellow... And they took Pete by himself, and I heard him say, "Now sit there, and hold still, and don't move!" You know, like that. Oh, I could not believe it... I took Pete out of there when he was finished, and we never went back. None of us. And I believe I phoned the receptionist and said I was appalled at how the dentist treated our child. I said, "He doesn't need that..." (2.53.26-54.3).

Julie recalled an incident where she spoke to a professional from a social service agency after Maria had had an accident.

> *Julie* But I just happened to mention, "Do you have insurance for this?" And ah, he looked at me as if I was a way out to lunch. He said, "Insurance?" And I said, "Well, yeah... to replace the teeth she's lost, and look at her jaw and her nose..." And he said, "We only have insurance if they die." And I said, "I beg your pardon?" He said, "We've only got insurance if they die." Well, nobody... She's not going to die... (2.55.29-56.3).

The response of health care professionals to their offspring was a topic that occupied the group's attention again in the third meeting (3.3.8-3.5.13). One member of the national council of Faith and Light shared her perception that some parents feel disempowered in meeting with health care professionals to assess caregiving and employment options for their offspring with an intellectual disability (J.Rogala, personal communication, September 22, 2002).

Staffing Changes

Participants commented on the difficulties their offspring experienced with changes in caregiving personnel. There were sounds of agreement around the group when Vicky disclosed Ursula's response to staff turnover.

> *Vicky* It's hard because she doesn't know who's giving the orders. Ursula can't talk, she can't say... The person that get to know her, have to be moved. They keep moving them, moving them, and that's what we had the meeting about... It's

> very difficult... She doesn't know... [Staff say to her] "Do this and do that," and [Ursula's response is] "Who the heck are you?" (1.23.16-21).

Vicky had observed that a change in driver with the daily transport could affect her daughter. "I could see in Ursula's face too, when she comes home, that she have a different person [driver], and she just no smile..." (1.24.7-8). Paul concurred in his experience with Henry.

> *Paul* We found that out at a very young age, and he was going to a special school and he got along so well with the driver, but then the driver went to Florida, whatever for three weeks, and [he] had a new driver, and it backfired... (1.23.30-1.24.1).

Hugo spoke of the difficulty new staff experience in understanding the subtleties and nuances of the ways in which Maria communicates (she is nonverbal), which impacts on her relationship with caregivers.

> *Hugo* ... she can transmit what she wants in her own way. Somebody that is looking after her, whether it be [the group home or the day care centre] when they're new, it would take a while for them to sort of grasp what she's after. So it takes her longer to bind with that person, because she's already got her favourites. "You're an outsider, I'll get used to you later on," type of deal... (1.43.12-17).

In the third group meeting, Julie reflected Hugo's sentiments when she described the impact of staffing changes on Maria, and how difficult it was for her as a mother (3.23.7-8). There followed a discussion on parents' dealings with support workers (3.23.19-3.26.18).

Wendy expressed similar thoughts in the second group, indicating the possible detriment to care.

> *Wendy* ... Well, if they're at school and they change... They don't have the same personnel that know that this child doesn't speak well or doesn't complain or anything... They don't pick up on it... (2.26.32-27.3).

She empathised with what offspring experience, when Vicky admitted that change in staff impacted her personally.

> *Vicky* ... There are times that's really hard sometimes... When you get to trust people and they're gone...
> *Wendy* ...Yeah... we know what our children feel like too... When they have

> people that are working with them and then they're gone. So it must be very confusing... (2.23.6-12).

Hugo and Julie had chosen to advocate over certain changes in personnel at a school Maria was attending. There was a satisfactory outcome.

> *Julie* We had to have a meeting with [a support agency] because the girl that did these programmes, and these children loved these programmes, was moved out of there into another situation. And we were really worried that these programmes would go adrift... And it's the handicaps [*sic*] that are suffering.
> But after that meeting that night we were assured the next day that... (I'm laughing because, we didn't think we could convince them, but we did)... that these two programmes... this girl came back to give these two programmes... (1.50.24-32).

Paul and Tina observed that collaboration and communication between support workers helped with changes in staffing (1.37.3-9).

The majority of participants expressed ambivalence around the standard of caregiving their offspring received outside the family home, which appeared to heighten parents' anxiety around launching their offspring. It appeared to make it more challenging for parents to trust other caregivers, and to relinquish care of their offspring. Paul and Tina had chosen to focus on the benefits that might accrue through Henry being cared for by others, which was reflected in their affirmation of Henry's caregivers. Parents revealed the importance of locating committed and competent health care professionals to care for their offspring, and expressed their appreciation for the care their offspring did receive. Finally, parents described the impact on their offspring of staffing changes amongst those caring for their sons and daughters.

Faith and Light

At the outset I had expected members of the group to have little difficulty in speaking about Faith and Light. Participants appeared to appreciate their membership with the movement, and that of their offspring. As the two groups unfolded it was clear that the particular challenges parents faced, and their concerns about caregiving for their offspring, were more immediate issues. It appeared that participants perceived only a

negligible correlation (if any) between the challenges they faced and what Faith and Light offered. Nonetheless, the participants were aware that part of the research question involved Faith and Light, and one participant in particular brought the group's attention to the matter on several occasions. Based on lines of transcript, Faith and Light was the third theme in order of significance that parents discussed (385 lines).

Participants on the whole spoke favourably of their connection with Faith and Light from their perspective as parents (194 lines) and from the perspective of their offspring (122 lines). As parents they appreciated the mutual support, understanding, interaction and friendship that they received through Faith and Light. Julie described the sense of community. "... There is also a feeling of community when we have the lunch and that together..." (1.44.18-19). They affirmed Faith and Light as a forum where their offspring could celebrate their gifts and express themselves, find acceptance and friendship and receive religious education. They offered some suggestions for improving the meeting format (94 lines).

A substantial proportion of field work data involved the theme of Faith and Light, including notes from local, national and international meetings and informal interviews with parents and recognised personalities within the movement. I have annotated with field work data those subthemes, where field work data confirmed or brought into question the findings arising from the focus groups.

For Parents

Mutual support and understanding.

The mutual support and understanding (77 lines) participants experienced at Faith and Light was the most mentioned dimension from the parents' perspective. Tina described how through Faith and Light she had gained a better understanding of caregivers.

> *Tina* Through Faith and Light, I also understand that the people that work with our son are doing the same thing that we do... I feel we're walking side by side with the handicapped. We are helping out both. The people that work with our son

> are doing the same thing. They [are] with him the whole day. It has taught me these things... (1.55.11-16).

Tina revealed that she felt "needed" at Faith and Light, and enjoyed belonging to the group (1.55.17-18). Paul reflected that by not turning up, "...We're letting a lot of people down... They'd be upset" (1.55.27-28).

Wendy recounted how supported she had felt at a weekend gathering she had attended, which was a foreign sensation for her.

> *Wendy* ... I've found the Faith and Light group, as a whole, when you go to the big meetings where you all sort of think alike as far as the handicapped people and you support each other. I can remember one time we went to a retreat, and this was early on, when we were involved with Faith and Light, and Pete and I went and he was having a particularly bad time... The medication wasn't working well for him, and we went with Tina and Paul, and he was having some difficulty. I can remember one person thought that Pete needed a lot of telling what to do... sort of like she became his employer almost... She was telling him, "Shhh..." and, "Don't do this and don't do that." He listened to it for quite a while, and then all of a sudden, he exploded... It was at a time where I think, it was a mass going on... There was something that was quite solemn... and I was trying my best to keep him calm. And all of a sudden, two men came over and they just dealt with Pete in such a calm quiet way. He calmed right down, and then someone started talking to me. And I thought, "Now this is support!" It was something I've never had before. And I came away from that, I was on a high. I thought Faith and Light has got to be the best... because I felt so much support... for myself... And no one had ever given me support like that before... nobody... (1.54.10-30).

She reiterated her appreciation of the support she received through Faith and Light both in the second group and in the third group meeting, stating that she had received more than she had given. "... You really need support and I think that's what Faith and Light gives us too... We have sort of a common interest..." (2.22.9-11).

> *Wendy* I mean sometimes you get upset, or you... I don't feel like going to a meeting today, but you go, and you're always glad you did, because you get more than you give, and so I've been thankful for all, all of you... (3.19.7-10).

When Julie referred to difficulties she was facing, and her need for someone to "sound off" to, Wendy pointed to the role of Faith and Light. "... Well, that's what we're all about, isn't it? ... As a Faith and Light family" (2.39.27-28). A mother who joined the third group meeting identified the purpose of Faith and Light as giving support to

families. "... that's the purpose of Faith and Light, is to give support to families" (3.2.14-15). As Vicky was leaving the second focus group she shared with the participants how positive the experience had been for her. In particular, she told others how helpful it was to listen to stories that participants would probably have not disclosed in the context of Faith and Light meetings. "... It was wonderful... We see each other so much at Faith and Light and we really don't know what we're going through..." (2.49.5-9). She intimated that the focus group dynamic gave rise to something beyond what was offered at Faith and Light. In a similar vein, Wendy saw the focus group process as an extension of her Faith and Light experience in listening to and supporting one another (2.37.10-11). One of the corollaries to the focus groups was the instigation of meetings outside the Faith and Light gatherings for parents to listen to each other's stories and to support one another. They agreed to meet in each other's homes. Wendy was instrumental in promoting these meetings.

Participant observation as a chaplain at local meetings over a three year period confirmed the importance for parents of the aspect of mutual support and sharing at the meetings. There was value in it for parents even if the disclosure to one another was more superficial than that which occurred in the focus groups. One participant did raise a deeply sensitive issue with several other members at a monthly meeting over lunch. The shared meal often provided an opportunity for parents to connect with each other. On the occasion of Peter moving from the family home to a residential Christian community, Wendy, his mother, and Peter were both able to share at a local meeting some of their thoughts and feelings around the transition. They appeared to experience a sense of support and being understood. One of the members of the International Council in an informal interview recounted from her own experience how much it had meant that there were those in Faith and Light who understood her feelings and thoughts around having a sibling with an intellectual disability. They were able to normalize her difficulties with behaviours of her sibling. While the Council member experienced frustration over her sibling's attention-seeking attentions, her fellow member in Faith and Light was able to assure her that for others gathered it was "no big deal."

Interaction.

Hugo emphasized that for him interaction was the essence of Faith and Light, capturing the thoughts and feelings of others (73 lines). "But the interaction, it's *it* [italics added]... Definitely is..." (1.63.12). Vicky disclosed how challenging it was for her when she joined initially to open up and share with others. She clarified that it no longer posed a problem. Paul attributed Vicky's increased confidence to the dynamics of the gathered community. "We have accomplished something... [You] have learned to open up..." (1.48.5-6). Paul and Wendy observed that the strategy of meeting together in one room facilitated the interaction (1.62.6-7, 20). Hugo believed that the mime and the singing also promoted the bonds between members. He quipped wryly that it was important for members to be able to follow others.

> *Hugo* Yeah, the bond is... mime and singing. Of course, we thrive on that quite a bit. But there is also the question of following... learning to follow somebody that is giving directions... (2.37.15-18).

One of the distinctive features of the local meetings was the interaction that took place amongst parents through the sharing and check-in, activities, worship, and eating together. While the age of parents was similar (mostly retirement age and older), their living situations were quite diverse (married, widowed, offspring at home or elsewhere). The differences did not appear to impede the interaction. Interaction is an important dimension that undergirds the planning meetings for each monthly meeting. The local community conducted a review of the strengths and the growth areas of its community life. In response to the questions, "Why is Faith and Light important to me?" and "What do I like about being together in this community?" several parents expressed appreciation for the interactional dimensions of life together. "I enjoy the feeling of community belonging;" "The relationships, the love and the support;" "It is an important community – we care for one another."

Welcome.

Parents identified to a lesser extent the aspects of welcome (23 lines) and friendship (21 lines). Hugo made comment on how welcoming he found the community.

> *Hugo* One thing about Faith and Light, that I admit is better than anywhere else, is when you walk in there, they know you. You know what I mean? If it's your first time, they make you feel at home. They come out and they say, "Oh, new face, huh?" Or something to that effect. The first one that hit me to find out who I was, when I came in, was Chris... He came up, and he says, "What's your name?" And I says, "Hugo." "Glad to know you. Do you collect licence plates?" (Laughter). It might have been a silly question, but it was sure an ice-breaker, I'll tell you... (1.61.1-13).

Paul saw the round of introductions at the beginning of a meeting not only as a way of connecting with each other, but also of showing care. "... They all care about each other..." Julie concurred by adding, "... and they all ask you, how you're feeling" (1.56.3-6). Hugo affirmed Paul for the role he plays in greeting people as they arrive for a Faith and Light meeting (1.64.3-4).

Welcome figured prominently in local meetings. Usually there was someone at the door to let people in and greet them. Informal gathering occurred before the meeting began. The meeting itself began with a formal welcome from the community leader, followed by a song, in which in each member in groups of four is named in the refrain, "We're so glad that [name] is here, because we love them so..."

Friendship.

Wendy expressed her amazement and gratitude that friends of their offspring would attend. Friends were a gift for the parents as well as their daughters and sons.

> *Wendy* ... And I think the other people we have come to know... the parents, the friends who come, have been invaluable... And sometimes I wonder why the friends come, because they don't have somebody that they're there for... But I guess they have this need too... of helping and they learn from that, and they keep coming back and back... And it's amazing...
> *T* So, it's good to have the friends coming along, Wendy?

> *Wendy* Oh, it's wonderful to have the friends... Because parents need the friends as much as the others do... (1.53.32-54.10).

She reiterated her amazement in the second focus group. "...I'm amazed by the volunteers who come, or friends, who don't have people... I'm just amazed by that..." (2.47.22-23).

For Offspring.

Participants gave voice to the ways in which they perceived that Faith and Light benefited their offspring and other people with an intellectual disability (122 lines). One of the principal charisms of the community was the way in which it called forth the beauty and the giftedness of its members (67 lines).

Revealing beauty and giftedness.

Wendy identified clearly her perception of one of Faith and Light's roles. "... and I think Faith and Light helps us to see the beauty of each one of these people who have developmental handicaps" (1.51.32-51.1). She continued with examples pertaining to various members of the community.

> *Wendy* ... When I think of Maria, I think of that spark in her eyes, and sometimes it's a devilish spark... Sometimes it's "I'm worried," sometimes it's... You can read her eyes. With Ursula it's a smile... I've seen her tell people with her eyes or her face to "Leave me alone" (laughter)... Don't have to say anything... And you know Brian, we've come to really appreciate his wisdom and Chris cares about everybody. And he keeps us all connected... He even knows about our families and where they're living and... brings licence plates and stamps... Each one of them has something so unique, that we never would have gotten to know about, if we didn't get together at Faith and Light (1.52.1-21).

Wendy saw people with disabilities as teachers. "... They're teaching us all the time. They're the teachers and we're the students" (1.52.27-28). Through its acceptance and valuing of their offspring, Wendy agreed that Faith and Light provided a forum wherein they could exercise their gifts and their ministry (1.53.1-4).

Julie expressed this theme as Faith and Light providing a place for their offspring to express themselves. "... These people [with disabilities] can express themselves in other ways even if they can't do it like us... They have their ups and downs much like we do..." (1.53.22-23). She remarked that being on the planning committee for the monthly meetings enabled her to appreciate better the qualities of individual members (1.63.26-29). She made particular mention of the holiness she saw in Chris that made him a natural fit for the part of Jesus Christ in mimes.

> *Julie* ... Everytime we have our meeting to prepare the programme, and they're looking for Christ, I always suggest Chris. He gives me that feeling that this is part of him... He has the look about him that is so holy... (1.53.8-11).

There was support amongst the participants for Brian's initiative in volunteering to sing unaccompanied at a recent meeting. It provided an opportunity for him to showcase his talent.

> *Hugo* ... Brian, last week, he sang OK...? And I never thought he could... It might not have been 100%, but at least there was enough to keep everybody involved...
> *Tina* ... and I think he was right to tell us that he liked to be involved... Maybe a bit more than he is, I don't know....
> *Julie* .... It was nice even to hear him say, he... I was pleased that he got up and said, "I'm going to sing a solo..." (2.42.29-43.21).

Growth and friendship.

The subtheme of growth and friendship accounted for 25 lines. Hugo shared about the growth they had witnessed in people with an intellectual disability. "... I mean, good grief, you see some progress from one meeting to the next" (1.51.16-18). Vicky spoke of how growth in Ursula translated into the home environment.

> *Vicky* ... Well, you know what, we're singing, "Thank you, God, for giving us home, and thank you God..." We're singing while we're brushing our teeth in the morning. I learned the songs and she just loves it... I sing to her... and it is nice... I like to go [to Faith and Light], Ursula likes to go [to Faith and Light]... (1.48.8-12).

Some of the personal growth in Ursula, Vicky believed had arisen through the friendships Ursula enjoyed in the group and the regularity of contact.

> *Vicky* ... She's different, we feel that we see the same people.... I call them Faith and Light friends. [I say to her] "We go see our Faith and Light friends." She likes to sing and she likes to see everybody... Now she got a big grin and smile on her face... (1.48.20-28).

Christian formation.

Julie and Hugo identified the role Faith and Light played in Maria's religious education.

> *Julie* ... but I feel that even watching the people there [at Faith and Light], it has educated me... Because I tried to get Maria when she went to Barradene school... we tried to get a nun to come there and teach some religion. Because Maria did go to church with us all the time, and the answer was, "What could they learn in religion?" So we were very happy to see that she was going to Faith and Light. Because if you just sit there and watch what's going on, those people are interacting with some of the skits you put on and some of the songs. There is an interaction and I really believe they know about... they've learned about God. The way some of the pictures are... it's more than pictures... it's people expressing themselves through pantomimes and singing... It's a beautiful concept that is going on in that short time (1.44.6-17).

Julie added later that she wished those in religious leadership could experience a Faith and Light meeting. "... More people in the religion aspect of the community should spend a time at Faith and Light, to see what is going on..." (1.55.1-2). None of the other participants emphasised this aspect of the movement's life. This subtheme (16 lines) and the following subtheme of listening and acceptance (14 lines) were only mentioned briefly.

Listening and acceptance.

Participants appreciated the space Faith and Light offered for people with an intellectual disability to be listened to, and suggested providing more opportunity for them. Wendy supported a time for sharing personal news at the beginning of a meeting. She reiterated that a flexible format for meetings promoted a culture of sharing and listening.

> *Wendy* ... I think when we sit in a circle and we all have a little bit to say about what has been happening in our lives... I think that is something they value. I know Brian loves to be able to talk... Chris and... I think it makes them feel important... and so it's not so organised... (2.40.29-41.2).

Julie agreed that Brian valued the chance to talk.

> *Wendy* ... But I do think, that they enjoy having more |
> *Julie* Sharing and talking... We do all week... Because they don't have anybody to talk to. I know when we go to the donut shop, and we see Brian there. And he's really happy to see somebody else. He wants to talk.... Brian was so happy to see us... "You guys are just as bad as me," he says... (2.42.31-32).

When Julie gave an example of what Brian might offer in a time of sharing, Hugo added that being listened to showed members that they were accepted.

> *Julie* Brian could have said, "I went to Tim Horton's, and I had my lunch, and... I didn't buy a coffee," or "I bought a coffee to go with it..."
> *Hugo* ... I was accepted, in other words, yeah... (2.45.28-32).

Wendy liked the non-judgmental atmosphere of the meetings that promoted acceptance and valuing of members. "... But there's nobody there that judges them. Everybody loves them, and values them for who they are..." (1.53.3-4). Hugo agreed with Wendy that flexibility in the meetings fostered a climate of sharing and being heard. He described Faith and Light as a "stepping stone" in opening the wider community to the people with an intellectual disability. Its flexibility played a key part.

> *Hugo* ... when you walk in some of them might be roaming all over the place but there's nothing that is structured... minute by minute programme. You see them all getting around. You get Peter that comes out with his guitar, and he plays... The other people say, "key of C" or "key of something else," and he's got it... (1.51.12-16).

He liked the fact that there were "no regulation time clocks." "...If you ready to eat at 12.00 pm, you eat at 12.00 pm. If not it's 12.30 pm... Well, OK, fine..." (1.62.27-28). At the same time he admitted it could be challenging. "... Sometimes, it's annoying to us people because patience is not a virtue to us..." (laughter) (1.51.27-28).

Suggestions for Improvement

Wendy advocated in the second group for greater opportunity for members to share their personal news. "... I think in the meetings we need more input from everybody" (2.40.29). She wondered whether too much time was spent in small groups where it could

be difficult to generate and sustain discussion. Julie pondered whether sharing in a large group could stimulate more interaction.

> *Wendy* ... Sometimes I think it's too much time spent sitting there... If we can get the core people to sort of open up, that's good... But sometimes, they don't say anything, so I don't know how interactive...
> *Julie*... Maybe we could have a circle, and... take, go round and say, "Well, what happened... or what was your world... for the last... done this week or for the month?" (2.45.1-14).

Wendy suggested a "show and tell" (2.46.24-25). She sought less structure in the meetings in order that people with disabilities have more opportunity for showing their talents. "... And I think you have to have more of that, more relaxed... and not so much structure..." (2.43.28-32).

Julie suggested more singing, while Tina thought that more activity with the singing might be helpful.

> *Julie* ... because it's a lot of religion and no play... And I would prefer a lot more singing...
> *Tina* Yes, that's one thing I was saying through summer. I said with the song we sang "We walk with each other," it would have been nice if we stand up and walk |
> *Wendy* Right, right | (Sounds of agreement from group)
> *Tina* a bit more action sometimes... (2.44.1-10).

It seemed on the whole participants were satisfied with the meeting format. Their suggestions for improvement occupied 69 lines of transcript across the two groups.

Participants acknowledged Faith and Light as a resource for themselves and for their offspring. The two aspects of Faith and Light that parents cited most for themselves were first, the mutual support and understanding, and second, the interaction, which they experienced. For their offspring, parents were most vocal about the ability of the community to reveal and call forth the beauty and giftedness of their ofspring. The other contributions of Faith and Light to their offspring were friendship and growth, Christian formation, and listening and acceptance. It seemed that parents desired more opportunity for their offspring to be involved personally at Faith and Light meetings.

Responses to Transition

The launching phase is generally recognised as one of the most stressful stages in the family life cycle. It brings challenges of its own for parents with offspring with an intellectual disability. This was the fourth theme to emerge from the data (280 lines). Participants referred to three transitions: between schools; from the school environment to the work environment; and from the family home to another residential setting. In the last instance, some participants recounted that there was often movement back and forth between the home and the residential setting, the dominant subtheme in this category (120 lines).

Continuing Ties

Wendy described the inadequacies in Peter's group home, into which he moved from the family home. He returned home every weekend, "along with his laundry, and then we'd go back and fill up the refrigerator. We were still taking care of him" (1.41.3-4).

> *Wendy* ... He was not able to cope with that situation... It wasn't safe. The three guys really didn't know what to do if the smoke alarm went off. They just let it ring. If the washing machine overflowed, the water would just keep running. There was so much damage going on. I'm surprised that we let it go as long as we did. Finally I said, "You're coming home." They were actually were going to move to another house and they wanted to take in a person that Pete just didn't get along with. I said, "That won't work, so until you find him something better he's coming home" (1.41.5-17).

It was clear that this arrangement found favour with Peter.

> So when we told Peter he was coming home, he just put his hands together and started wringing them back and forth with a big smile on his face.... He was so excited. "Thank God I'm going home..." So he's been here with us now for six years, back home again... (1.41.17-24).

Paul and Tina placed Henry into institutional care when he was 17 years old. Henry returned home when caregivers in the institution went on strike. Tina and Paul were given a choice when the strike ended.

> *Paul* ... [A representative from the institution] said, "Well, you've got so many weeks to make up your mind, and otherwise we put somebody else," because they

> have a long waiting list. There was somebody waiting for that bed, so we either had to let it go, or he would have lost his spot. And he still would be home today if we had done that... (1.21.17-21).

It remains part of their strategy not to allow Henry to remain at home too long when he returns.

> *Paul* ... But we never let him stay home too long. We said, "You didn't bring pyjamas, you got to go back now".... But the longer he stays the more comfortable he gets at home, and he sometimes says, "I am going to come for good" |
> *Tina* The last two times he says, "I am coming home to stay." That's when he arrived, that is what he says. But, I understand that a bit.... Maybe, it's because of the Christmas decorations. He used to come over for two weeks, when he was at [the institution], and maybe it has something to do with the time of the year... Just that they cannot tell us... (1.27.28- 28.12).

Nonetheless, Paul and Tina admitted to continuing challenges they faced as parents. Paul described the difficult situation they had encountered the previous day in having Henry home for a day from his group home (3.19.12-3.21.3). Henry had stated that he intended staying in the family home. In response, Paul had allowed Henry to see a fierce dog they were looking after, knowing that Henry was frightened of dogs. Henry returned to the van. Tina disagreed with Paul's actions, as did Henry's support workers. Paul expressed the tension, "You're damned if you do, and you are damned if you don't..." (3.20.23).

Julie described the to and fro nature of Maria's first year in the residential Christian community. "... The first year she was back and forth to us a lot, because we couldn't leave her" (1.27.11-12). She now returns every second weekend, for public holidays and for four weeks during summer (2.34.20-30); and "in between when mother gets too lonely," Hugo chipped in (1.29.25). Julie admitted, "I would take her back home today if I could" (1.29.11-12). "We're very, very involved with Maria" (2.34.26-27).

Participants whose offspring have left the family home have adopted markedly different strategies in dealing with the transition. Even with their son Henry well established in a group home, Paul and Tina still need to be clear and firm with boundaries. Wendy recognised that the residential arrangement for Peter was not a good fit, and had little other choice than to take her son back home. Julie and Hugo reluctantly sent Maria to a

residential Christian community, and now it seems would gladly welcome her back if they could. Maria appears to spend more time back in the family home than Henry. Her returns to the community remain painful for Julie. It was clear from the participants that irrespective of the stance they adopted when they launched their offspring, it remained a challenging and painful transition.

Leaving Home

For some of the participants, it seemed that moving offspring from the family home into another residential setting was even more painful than the school-leaving transition (68 lines). The time came for Hugo and Julie when for health reasons they needed to find alternative residential care for Maria (1.26.4-5). Julie used a vivid metaphor to describe her recollections of the day of Maria's departure for a residential Christian community. "It took nine people to move her into [a residential Christian community].... And we carried buckets with us to catch the tears..." (1.26.23-31). Five years on, Julie reflected, "... Even to this day there are some times that I take her back [to the community] and it hurts me..." (1.27.13-14). She revealed the continuing difficulty she experiences in accepting that others could care for Maria. "... And it is still hard for me to accept... to be in here (pointing to heart) that somebody can take care of Maria... It's hard..." (1.30.26-32). Julie articulated the difference for her in launching her four natural children without a disability and in launching Maria.

> *Julie* This is the hardest, I feel... I had four children... They left home and I went through a bad period. The last one, my daughter left home. But with Maria it was different. She couldn't fend for herself, and I knew she would always need me, regardless of where she went...
> *T* Even if she was at [a residential Christian community] she would still need you...?
> *Julie* ... Regardless of where she went, I still feel that it isn't as bad as the other ones leaving home [*sic*], though I did go through a bad period when they left home. But hers was the worst, because she cannot talk or deal for herself... (1.42.11-22).

In the third group meeting Julie related the *terror* that other parents had expressed to her over the prospect of moving their offspring to a group home.

> *Julie* … They're [other parents] shutting it [other residential options] from their minds, because they are *terrified* [italics added] of letting their son or daughter go into a group home, because they've heard so much… and there's so much in the paper too… about these group homes, and what is happening in these group homes… (3.22.12-16).

For her husband Hugo, the most painful aspect of launching came some years earlier.

> *Hugo* The two worst parts of what you call separation was when the province came back and said she was 18 years old, she was no longer a ward of the province. She was a child of God. Nobody could back up on nothing [*sic*], not even the organisation that she was under (1.25.20-24).

He expressed gratitude for the assistance of two social workers with negotiating the transition.

Tina disclosed how painful she had found moving their son Henry out of the family home.

> *T* … I imagine it's quite difficult to let go in that regard…
> *Tina* Oh, it was hard, very hard… for me especially…
> *T* … I imagine as a parent, especially for a mother, that it's an incredibly difficult thing to do… I imagine it's something that takes a number of years to be able to do…
> *Tina* Oh, it does… Yes… (1.1.24-31).

Wendy described how a counsellor had suggested that Peter's moving into a group home might assist with the depression he was experiencing. The counsellor wondered whether Peter was finding it difficult to cope with the independence that his two younger sisters were enjoying (1.38.25-31). She recounted Peter's response on launch day.

> *Wendy* … I now get to the day of the move. We told him, "Tomorrow's the day that you're going to go to this place." So in the morning we got up and we had packed some of his things in boxes, and we said, "Pete, it's time to wake up because we are going to have a moving day today." Before he got out of bed, he started to open his eyes and he said, "I was wishing this day would never come" (1.39.23-29).

Wendy recalled the thoughts that crossed her mind. "What are you doing to this child? It is something he doesn't want." With her husband they decided to proceed. She found the day increasingly difficult. After moving Peter's belongings into the group home, Wendy and her husband accompanied Peter to the bank with his support worker.

> *Wendy* ... So [my husband] went to his car, and I had my car [because] we needed them both to move him. And I can remember watching him, go into the bank with the social worker, and his Dad going to the car and Peter would not go in that bank. He just kept looking at his Dad, just kept watching his Dad. And I started to cry, and I thought, "This is really... this is bad stuff." But eventually his Dad went home, and I cried all the way home, in my car. But it didn't get better, it got worse... (1.40.15-22).

Ursula remains at home with Vicky. Vicky used the word "terrified" twice in the third group meeting in describing her feelings around exploring other residential options for her daughter (3.33.26; 3.34.10). She later identified the ambivalence she continues to experience in looking to her daughter's future.

> *Vicky* ... I am scared because... as we talk, one minute when I'm not feeling well, I'm in panic that she won't have no place to go, but when I'm feeling OK, I said, Well, I can manage, I want her home with me... (3.38.9-12).

Vicky reiterated that Ursula's inability to speak heightened her anxiety (3.38.23-31). Ensuring that Ursula's residential needs were responded to, took precedence over arrangements for Vicky's own care. After some participants had expressed their considerable concerns over some nursing homes, Vicky responded,

> *Vicky* ... my mind is so forward, caring and worrying, and hoping that everything will turn out well, that I don't even think of myself. I couldn't care less whether they put me in a hall [nursing home], as long as she is happy... (3.40.20-23).

The participants in the third meeting spent significant time discussing other residential options. Participants shared stories of their knowledge and experiences of different group homes (3.27.18-3.31.12; 3.32.12-3.36.17). They identified those aspects of residential options that they appreciated, and those aspects they found difficult. Those they liked included: involvement with the family prior to the son or daughter moving to the new residence (3.27.22-3.28.5; 3.36.10-14); monitoring of food intake (3.29.1-3.30.13); support workers staying over night (3.30.30-3.31.12); a caring environment – attention to personal hygiene and physical appearance of offspring (3.32.9-3.32.29; 3.35.19-22); the physical state of home (3.34.23-31); activities for residents (3.30.19-23; 3.36.14-17). Aspects they expressed discontent over included: inadequate organisation and supervision (3.28.16-23); and institutions (3.39.5-11; 3.39.30-3.40.13).

Leaving the family home was not the only transition that parents referred to. While launching offspring appeared to be the most challenging transition, characterised by ambiguity over parents' continuing role as caregivers, transition between schools and from the school setting to the workforce or a workshop could also be demanding.

Leaving School

It seemed that schooling for participants' offspring provided some measure of security. When Julie mentioned that Maria was still in school (even though she was 32), Tina remarked to Julie, "...The fact that you could continue [schooling], that's very good in some ways..." (2.34.15-18). In the same vein, when the time came for Peter to leave school, and commence in another school and work setting, Wendy recalled her anxiety. The move necessitated a commute across part of a busy city.

> *Wendy* ... And he started going off to school, I mean to school and to work, on his own. That was a very big separation, because I didn't think he could even cross the street carefully on a... And then they are telling me, "You have to send him across town by himself, you have to train him, and then he has to do it on his own in order to come to this school..."
> *T* Was that the toughest time for you as a Mum?
> *Wendy* Yeah, I think so... That was one of the toughest times... (1.14.26-31).

Wendy described her panic when she lost Peter in the subway when she was training him to take transport (1.13.11-15.16). She described being "nervous all the time," with the additional responsibility of "trying to deal with the rest of your family" (1.14.8-9). This subtheme accounted for 52 lines of transcript.

Of the participants who had launched their offspring, it seemed that Paul and Tina were the most definite about boundaries they needed to maintain between the family home and Henry's group home. They were also the parents who were most articulate about their experience of *letting go*, a subtheme occupying 40 lines of transcript.

Letting Go

Tina and Paul were united in their pragmatic rationale for placing their son outside the family home.

> *Tina* ... The younger they are, the easier they can adapt...
> *Paul* ... You know that someday you have to *let go* [italics added]. And the older they get, the harder it is going to be (1.20.18-23).

After Vicky and Julie had expressed reservations about the ability of others to care for their daughters (1.19.26-20.7), Tina asserted her thoughts.

> *Tina* ... But at the same time, I feel that our son, might have become more independent, that he can get something out of other people, because everybody is different. He can learn something, and that's my way of letting go. We think that other people can do good... (1.20.9-12).

Tina reiterated this stance in the third group meeting. Her attitude in liasing with the team leader responsible for her son's care involved the recognition that perhaps the team leader now knew her son better than she did as a mother (3.26.20-24).

Paul emphasised his view that parents could not protect their prodigy day and night (1.34.32). Paul and Tina recognised that their ability to let go and allow others to care for their son was integrally related to their ability to trust. Trust like patience was something that they had had to learn.

> *Tina* No... it's hard for us to trust whoever, but we have been learned to trust...
> *Paul* You have to... *you have to* [italics added]... not by choice...
> *T* You have to... you realise that you just need to trust...
> *Paul* Yeah...
> *Tina* Oh yes, yes... (1.35.1-10).

The trust implicit in letting go was also a choice. As mentioned previously, an additional part of their strategy in reinforcing Henry's launching and their letting go was clarity and firmness with the length and frequency of Henry's visits to the family home.

Wendy implied that she and her husband had decided to go with the process and see what happened in allowing Peter to be placed in a group home. It entailed letting go. "... But

we said, 'Well, give it a try, see how it's like.' So he went along with it, and we went along with it..." (1.40.7-8). Unfortunately, it did not prove to be a good fit for Peter.

Transitions are stressful for families. It appeared from the data that for some of the participants a degree of ambiguity surrounded their offspring's leaving the family home, with varying degrees of continuing contact and care. While the move from home to another residential setting appeared to be the most challenging transition, parents also recounted the demands of transition between schools and from the school environment to a work-type setting. Only one set of parents was explicit about a need to let go their offspring.

Stories from Earlier Years

All parents at some stage over the course of the two focus groups took time to share with other participants stories of raising their offspring with an intellectual disability (230 lines). Paul spoke of the process of recognising his son's disability, of schooling, of the challenges of raising other children without disabilities, and of the death of their other son (1.4.3-1.7.1). Wendy recounted the differences she experienced with her husband in accepting their son's disability, the process of diagnosis, the response of Peter's siblings, his education and incidents of abuse while at school, and challenges in changing schools (1.7.25-1.15.16).

Hugo outlined the challenges that Julie and he faced when Maria, aged 14, came to live with them after having spent her life in institutions.

> *Hugo* She couldn't talk, she couldn't walk, she wasn't toilet-trained... she couldn't speak, she didn't feed herself or nothing. So we walked backwards from what you people did. You had the opportunity to teach as you went... We took fourteen years in an institution, and tried to make it a home. Yes, it was a study. It was an awful big task. We had to do a lot of improvisation to adapt to make sure she did (1.25.14-20).

He repeated his account in more detail in the second group (2.35.7-36.1). Julie expressed some awkwardness in the first group owing to their not being Maria's biological parents

(1.3.28-4.1). It was a factor for them, which distinguished their experience from that of other participants. Hugo stated how much their lives had changed with Maria's arrival.

> *Hugo* We, right from the start [when Maria arrived], had decided that we weren't going to change our style of life, and soon found out that we didn't have a choice. We used to be social bugs and be all over the place visiting, and partying, and all that kind of stuff. Of course that all went out, because you couldn't trust a baby-sitter to do what Mum would do (1.25.31-26.4).

Vicky recounted her challenges in teaching Ursula to colour (1.49.20-30), and in the second group gave an extended account of Ursula's birth and early years, the testing and diagnosis and efforts at rehabilitation (2.11.29-15.22). She also spoke of her own childhood experience with mental illness/intellectual disability (2.10.31-11.28). Vicky shared her memories of being with Ursula at a civic fair (2.4.22-27) and Paul spoke of time with Henry at Canada Wonderland (2.5.7-13).

It appeared that irrespective of the focus of the group it was important for parents to be able to talk about their offspring, and particularly about recollections from their early years. It became clear that raising a child with an intellectual disability was a process with many unforeseen challenges. It was a process that required parents to have an unwavering commitment to their offspring and an investment in their development.

Devotion to Offspring

Amongst the participants, three sets of parents lived with their offspring with an intellectual disability. Ursula lived with her widowed mother Vicky in an apartment; Peter was at home with his parents Wendy and Jack. Maria lived in a residential Christian community and returned to Hugo and Julie's apartment every other weekend and during holidays. Henry was settled in a group home in a nearby town and returned to Tina and Paul's home occasionally. Whether or not their offspring remained in the family home, parents on the whole remained vitally concerned for the well-being of their offspring (167 lines).

Vicky's life seemed inextricably intertwined with Ursula's life.

> *Vicky* It's always on our mind... at the back of my mind, even when she's at the shop, or somebody caring for her, my mind is always... always on her, [whether] she's OK... (1.18.25-27).

> ... but I cannot imagine my life without her... there's no reason for living for me. I've nobody else. I don't want to live any longer, if I can't have her any more... (1.19.20-26).

The commitment appears to have arisen from a recognition of Ursula's dependence and a lifetime of caring intimately for her daughter.

> *Vicky* I think that our children like Maria and Ursula have high needs. They are not independent in anything |
> *Hugo* No defence |
> *Vicky* They need us more... and we're there from... wiping their nose, to what-not... Everything, we have to do everything, for them. I have to do everything for Ursula, and I think, that's why... I know every part of her body, every little pimple on her, or anything... (1.32.32-33.18).

In the second group Vicky described how she sees her daughter. "I still call Ursula 'baby'... 'giant baby'..." (2.9.17). At the same time Vicky repeated her desire to encourage Ursula's independence through taking public transport (1.1.10-11), and to facilitate her dependence on people other than herself.

> *Vicky* ... and she's used to that she goes away with somebody else, not always with Mum... and I don't want to take that away from her... It is good for her to depend on other people... (1.1.15-17).

Wendy's awareness of Peter's vulnerability fostered her sense that his needs were a priority for her.

> *Wendy* ...and you're trying to deal with the rest of your family and they're very supportive and they're very loving to [Peter] and everything, but... he kind of comes first... When you have a handicapped child, they come first, because you know that they are not thinking like the other children, they don't have that reasoning, and we were told early on that, that something he would always need, kind of looking after because he doesn't have a lot of reasoning power... (1.15.11-19).

She shared Vicky's perspective on how she sees Peter. "We still see them that way [as children], but they're not children any more..." (2.9.9). She used the vivid image of

offspring "grabbing the heart" of parents (1.32.30). Wendy acknowledged that she regarded Peter as part of herself (1.32.25-26).

Julie admitted that she also still looked upon Maria as part of herself, even though Maria now lived in a residential Christian community. "Oh, yeah... she's still mine, she's still part of us..." (1.18.8); "... She's part of me... she's ours" (1.32.23); "I can read her mind" (1.44.2). Julie's self-identity appears to include her being the "protector" of Maria. "You still have that feeling you're her protector... regardless of where she goes..." (1.18.17-21); "I'm very protective of Maria" (1.32.16). At the same time Julie expressed some ambivalence around her stance.

> *Julie* ... In a way that I think that is a bad mistake to be that protective of her. I know other people can do for her just as well as we can, but it's hard to understand that, and to accept it (1.32.20-22).

She acknowledged her belief that no one could care for offspring with an intellectual disability as parents could (1.19.26-29). It appeared that part of the reasoning lay in her conviction that Maria was a divine gift to them. Hence, Maria remained their responsibility.

> *Julie* ... To be in here (pointing to heart) that somebody can take care of Maria... It's hard... Maybe it's because the way she came into our lives, I know that God sent her to us... (1.30.31-31.1).

Parents' devotion to their offspring could translate into significant self-sacrifice as Vicky and Julie testified to in the second group.

> *Vicky* ... and I went back to work when [Ursula] was 7 months old, I found a baby-sitter... He [a doctor] said this little girl needs a mother, more than you need the money. I quit right then, and I never went back to work again... I was just... not enough to have time... All I wanted just to buy a home and have a little house... for my own self... you know... We were so new to the country, and we were very lucky with jobs... (Heavy sigh) (2.13.1-7).

> *Julie* ... Because, when we're both working, I'd get up at five in the morning... and I get ready for work... and I would call her, get her washed and dressed... and then Hugo would drive me to work, because we only had one car. And he would come home and feed her her breakfast. And then he would take her to school and then he would go to work. And then, we reversed it at night... But, I was in a job that was very demanding, and sometimes I couldn't come home, until seven and eight o'clock at night... (2.33.23-30).

It was evident that parents were highly committed to their offspring and that commitment came with a cost at times. Parents were also aware that their sense of commitment might not always be beneficial for their offspring. They expressed some ambivalence around their parent-offspring relationship. Nonetheless, their commitment had assisted them to weather some of the storms of raising their daughters and sons. Participants referred to two lessons that they had learned through parenting their offspring.

Lessons Learned

The final theme to arise from the data was the insights that parents had gained through their offspring (153 lines). The degree of participants' involvement in their offspring's upbringing had given parents a remarkable degree of empathic attunement to their daughters and sons with an intellectual disability. Parents demonstrated an acute awareness of the nuances and subtleties of their offspring's personalities and their needs. This was the first learning (122 lines). The second lesson for parents was the virtue of patience (31 lines), although some participants admitted that this remained a work in progress.

Attunement to Offspring

As might be expected of parents regarding their offspring, participants had learned some of their particularities. Participants appeared to enjoy sharing stories that revealed the personalities of their daughters and sons. Many of the accounts demonstrated how people with an intellectual disability are able to communicate their needs and their desires, even when they are nonverbal.

> *Julie* ... but she doesn't speak, she doesn't... Although you look at her eyes, and her expressions you can tell there is something going on in Maria's head... She didn't speak but she can call "Mama" |
> *Hugo* | When she's mad she calls "Daddy" |
> *Julie* | She did a lot to change our lives... (1.31.1-8).

Hugo testified to Maria's ability to communicate her food preferences.

> *Hugo* She amazingly could do a lot of communication, but it is not something that you could pick at the first meeting. When you first run into her… you can't. Like, for instance, she comes to the house and you give her her food, and she looks and she watches the fridge and you don't do nothing, she watch the fridge... and then she start whining. Then that's OK, she'll go and try to pull the chair away. 'OK, hang on.' You open the fridge, you grab the jug of milk or the jug of chocolate milk, because if it's white, well you're going to make it to chocolate. You start pouring… and she's made sure that the chocolate milk comes and that's her start of the meal…. She can transmit what she wants in her own way. Somebody that is looking after her, whether it be [a residential Christian community or an institution] when they're new, it would take a while for them to sort of grasp what she's after, so it takes her longer to bind with that person, because she's already got her favourites. "You're an outsider, I'll get used to you later on," type of deal… (1.42.30-1.43.17).

Julie and Hugo reiterated Maria's ability to discern those she wished to invest time in being with.

> *Hugo* And I think that, that they [people with an intellectual disability] have an immunity [*sic*] for selecting the people that they are going to like, and the ones that they don't like, you know, whether it's school staff or teachers or otherwise… (1.34.3-5).

Julie concurred later by adding that "even the handicapped person [*sic*] has the will to trust and not to trust." For Julie it was clear when Maria did not trust someone (1.35.12-14). Hugo had observed in Maria an ability to "bind faster than the normal person" relationally (1.35.22). Julie emphasised that "these children are not (I hate to use this word) 'stupid,' these kids are smart, and they just need that caring person to bring it out in their life" (1.44.3-4). In the second group Hugo reaffirmed Maria's ability to transmit her thoughts and feelings.

> *Hugo* She doesn't speak. She says "Mama." And "yoghurt more"… something like that. When she's annoyed, I could tell… anybody else could tell. She says, "Papa" or "Daddy." Then that means, "You haven't answered me, what I wanted. Wake up!" She can speak better with her eyes, than I can with my mouth. (Sounds of agreement) (2.35.27-36.1).

Paul gave an example of how Tina and he and other caregivers had learned to respect Henry's wishes. It arose when a support service was moving Henry into a group home. The first attempt did not succeed and Henry ended up in a psychiatric hospital for 18 months (1.21.29-31).

> *Paul* ... And we were not sure whether [the support service] would want to try it again, but [they] said, "This time we do it when he's ready." The first time they said, "That date" (November 22 or whatever), "that's the day he's going to move." But Henry |
> *Hugo* He wasn't ready |
> *Paul* No, he wasn't ready. So the next time they really took him a couple of times there, they visit and feel around how he reacted... (1.22.3-11).

Vicky remained at a loss to account for how Ursula had understood the death of her father. It appeared to intrigue other participants, particularly from the perspective of how to explain this experience to offspring with an intellectual disability.

> *Julie* But how did you explain to her that her Dad wasn't coming home? How did she deal with it?
> *Vicky* I told her that "Poppa's gone to heaven... Poppa's been very sick... And now it's only you and Mama..." I don't know where she got it, or if... I still can't understand it. We took the casket to the church and some people brought the casket over. And she went with me to church... I didn't take her to the funeral home though. And when they were lowering the casket, Ursula said "Poppa." She pointed right at the casket...
> *Paul* ... So she understood?
> *Vicky* She knew that it was Poppa there... It's amazing. How could she know? And still to this day, every day, every night we pray... And she's the one who starts, "God bless Poppa." She'll [pray] "God... bless ('da')..." And I wait... She says "Poppa." She could never say "Daddy"... (2.19.1-18).

Patience

Paul was the first participant to identify patience as something he had learned in raising Henry. It immediately struck a chord with other members of the group.

> *Paul* We don't know yet what lays ahead of us, but we take it one day at a time, but one thing you learn is "be patient"...
> *T* ... be patient |
> *Paul* be patient, you never have too much of that... because time is always on your side...
> *T* Right... in what sense do you mean time is on your side, Paul, because |
> *Paul* Well, something is going to happen sooner or later, and it probably be later. They say, "If you don't like the weather today, wait 'til tomorrow... it's going to change..." (laughter around group). And that's the same with the handicapped |
> *Wendy* One day at a time... (agreement around group) (1.7.13-29).

Wendy elaborated upon her experience of growing in patience, seeing it as a divine gift.

> *Wendy* ... There's a solution for every problem, but you just have to wait long enough for it |
> *T* You have to wait long enough, so you agree that patience is |
> *Wendy* Oh yeah, I think that... I don't think I had a lot of patience when I was first starting to have children, but when Peter came along, that something God gave me was some patience... That helped all the children, not just Peter... (1.8.5-12).

Later in the first group Wendy expressed her support for board members of a residential Christian community. "... They're learning like we had to learn... And sometimes it just takes patience..." (1. 59.21-22). Patience facilitated learning for parents and others alike. In the second group Wendy and Tina concurred with the circulated reflections arising from the first group listing the learning of patience as a key insight.

> *Wendy* That first one is right on... about learning patience. Right on... (2.8.23)
> *Tina* ... Yeah, very true... to me too... (2.8.28).

While Hugo and Julie appeared to concur with the need for patience, Julie mused playfully whether it was something she had acquired. "Well, patience for me is a little... (Hugo looks at her and there is laughter) misnomer" (1.32.11-12).

The most significant learning for parents appeared to be their nuanced understanding of their daughters and sons. Several of the participants described their growth in patience during their parenting. All participants (Tina appeared to concur with Paul) made reference to the individuality of their offspring with an intellectual disability and their particular ways of communicating.

Summary

Identifying themes in transcript remains an interpretive exercise, in which the worldview of the researcher will influence results. The assistant moderator did review the proposed themes, and concurred with them. She did not suggest any additional themes. Allowing for the limitations associated with assigning a numerical value to the identified themes, it was obvious that some themes occupied more of the group's time than others. Parents

wanted most to discuss the challenges they had faced and continue to face, with the issue of abuse being uppermost. They were concerned about the adequacy of caregiving that their offspring had received, were receiving, and would receive outside the family home. They identified aspects of Faith and Light that they appreciated for themselves, most notably the support and interaction, and for their offspring, principally the revealing of their giftedness. They expanded upon their experiences of transition for their offspring, portraying the degree of ambiguity that can surround offspring leaving the family home. Parents found it important to recount stories of their daughters and sons from earlier years, and spoke openly of their degree of commitment to their offspring. Finally, participants identified what they had learned through parenting, particularly their high degree of attunement to the personalities of their sons and daughters.

These were the identified themes emerging from the data. A next step in qualitative research is to examine the themes closely for an organising concept or theory that might be underlying. Is there a central phenomenon that is consistent with, and related to the emergent themes, which assists with explicating parents' reported experience? If so, what might related social science theory have to say to the proposed organising idea? It is these questions which guide the discussion of the findings in the following chapter.

Chapter Seven

DISCUSSION

Opening Reflections

There are three foci of academic endeavour in this project. First, there are some preliminary thoughts offered around an approach to pastoral care that I have termed theological pastoral care and counselling. Second, there is an exploration of some of the defining features of the Faith and Light community. Third, there is a study of the reported experience of member parents of a Faith and Light group around the launching phase in the family life cycle. In this chapter I turn to the third area of enquiry, in a quest for an organising concept that might underpin the themes identified in the previous chapter.

It was after the second focus group that my own agenda in the study of parents' experience became clearer to me. I wanted to hear how Faith and Light had contributed to the lives of the participants' families, including the lives of their offspring with an intellectual disability, from a pastoral care and counselling perspective. I had hoped that the data would show that one of Faith and Light's particular roles in the lives of families was its impact on families' belief systems or sets of values.

That was my agenda. It was not that of the group. Parents simply wanted to tell their stories. They did not want to be confined to issues "at the launching phase in the family life cycle," although it did appear that this was one of the most challenging phases in the family developmental history. They wanted to tell their stories about the birth of their babies; about the grim truth that their babies were "different;" about the marathon of specialists' appointments and the false hopes of favourable diagnoses; about the long and painful passage of acceptance of their children's conditions; about teasing, persecution and abuse of their offspring in schools; about the pain of separation when their offspring left the family home for another residential setting; about their considerable worry and

concern over the adequacy of the supervision and caregiving their offspring were receiving when they were out of their parents' immediate care and protection; about their fear of what would happen to their offspring when they as parents could no longer care for them. They recounted their investment in their offspring, how they thought of them incessantly, how they dreamed of them even after they had left home, how they even regarded their offspring as part of their very being.

What emerged from the data was that while all participants were committed and faithful members of a Faith and Light group, and while Faith and Light was important to them, and in most cases to their offspring, they preferred to talk about their experiences with their offspring rather than about the launching phase, Faith and Light or the influence of Faith and Light on their families. In retrospect it seemed obvious that they would want to talk about their experiences with their offspring. It is what they have lived and continue to live every day of their lives. The launching phase is a nebulous concept for them. In two cases, it had not occurred. In another the parent had placed her son in a group home only to have him return to the home five years later because of its obvious lack of suitability. In yet another, the parents remained vitally involved in the management and care of their daughter, including having her home regularly, while she was living in a Christian residential community. In the last case, the parents appeared in conventional family life cycle terms to be negotiating successfully the launching phase with their son established in a group home. Participants have been involved with Faith and Light for a decade at most, and Faith and Light meets as a group for several hours once a month. Obviously their offspring would be a more immediate topic for parents than the launching phase in the family life cycle or Faith and Light.

The data divided the research question into two distinct parts (a) the experiential world of parents as they faced launching their offspring with an intellectual disability, and (b) the role of Faith and Light as a provider of pastoral care and counselling in that context. In the first part of this chapter I respond to part (a) of the research question, by identifying an organising concept that appears to underlie the themes identified in the previous chapter. I have termed the phenomenon *perpetual parenthood.* I continue by outlining

those themes articulated by parents that contribute to this phenomenon in their lives, and I explore the central existential ambivalence of holding on and letting go that accompanies perpetual parenthood. In the second part of this chapter I examine relevant theories from the social sciences that might assist to explicate further the phenomenon of perpetual parenthood including: a systemic perspective outlining the biophysical, psychosocial and spiritual-vocational dimensions in family life, Bowlby's attachment theory, Boszormenyi-Nagy's concept of relational ethics and asymmetrical parent-child relations, Ricoeur's narrative theory and re-storying, and grief theory and the concept of relocation. I conclude with an outline of a pastoral theological perspective on leaving home, with some suggestions for the use of ritual.

Perpetual Parenthood

This research project has studied the experiential world of a group of parents as they face launching their offspring with intellectual disabilities. Traditionally launching is one of the defining moments of parenthood and family life. It is a nodal point. Family members, including parents, are groomed for this moment. What happens when parents realize that there may not be a clean launch of their offspring with an intellectual disability? Or when they realise that it could happen significantly earlier or significantly later than in conventional North American families?[178] Or when they realise that it may not happen at all? What happens to parents' self-identity and their understanding of their parental vocation where launching does not occur?

What emerged from the data was a heightened sense amongst the participants of their vocation as parents. For some of these parents it appeared that they carried a sense of never being "off-duty." Without a reasonably clear launching phase as may occur in conventional middle-class North American families, parents of offspring with an intellectual disability appeared to see themselves as parents in perpetuity. Practically speaking there is no hope for them of a reversal of the asymmetrical parent/child

[178] It need to be noted that recent census reports indicate that owing to economic factors "launching" in conventional families might no longer be as clear-cut and definitive as it once was.

relationship that typically occurs in families of children without a disability. I refer to the phenomenon as *perpetual parenthood.*

It was in the third focus group meeting that participants were most specific about this dimension of their parenthood.

> T It seems to me in terms of listening to your stories, that whereas other parents accept that at some stage, their kids are going to… to grow up and leave home, and they can look forward to retirement, or to time to themselves, and to be doing more leisure activities, for many of you, you don't ever stop being parents…
> *Paul* … It goes on and on, there's no end…
> T … Do you accept that you are going to be parents for the rest of your lives? |
> *Paul* It gets even more complicated | (3.9.10-22).

I reflected to the group that it had seemed to me on an analysis of the transcripts from the first two focus groups, that the holding on/letting go of their offspring was a central tension for them as parents (3.38.14-20). Hugo and Julie responded later by affirming the enduring nature of their vocation as parents.

> *Hugo* … You have to remember that parents of a disabled child, it's for life. It isn't with any other child at all…
> *Julie* You still have to be involved in the child, even if it is in another home…
> T It seems like even if your children are placed in a different home or residential setting, you're still fairly involved with the life of your child…
> *Hugo* You have to be… (3.39.18-28).

I suggest that perpetual parenthood may be an organising concept that underlies the other themes identified in the focus groups. That is, there are specific issues for parents of offspring with an intellectual disability that may explicate and substantiate the suggested phenomenon: the challenges parents face, particularly around the threat of abuse and the need to advocate for their offspring; their concerns over the adequacy of care their offspring receive from caregivers and health care professionals; the impact of the various transitions across the life cycle for parents and offspring alike; and parents' investment in their offspring and their peculiar knowledge of them. Themes raised by parents in the focus group discussions may contribute to, and be explained by, the phenomenon of perpetual parenthood. It is beyond the scope of this enquiry to explore the precise nature

of the relationship between the identified themes and the phenomenon of perpetual parenthood. I suggest that they may be correlated, rather than necessarily causatively linked (see Figure 2).

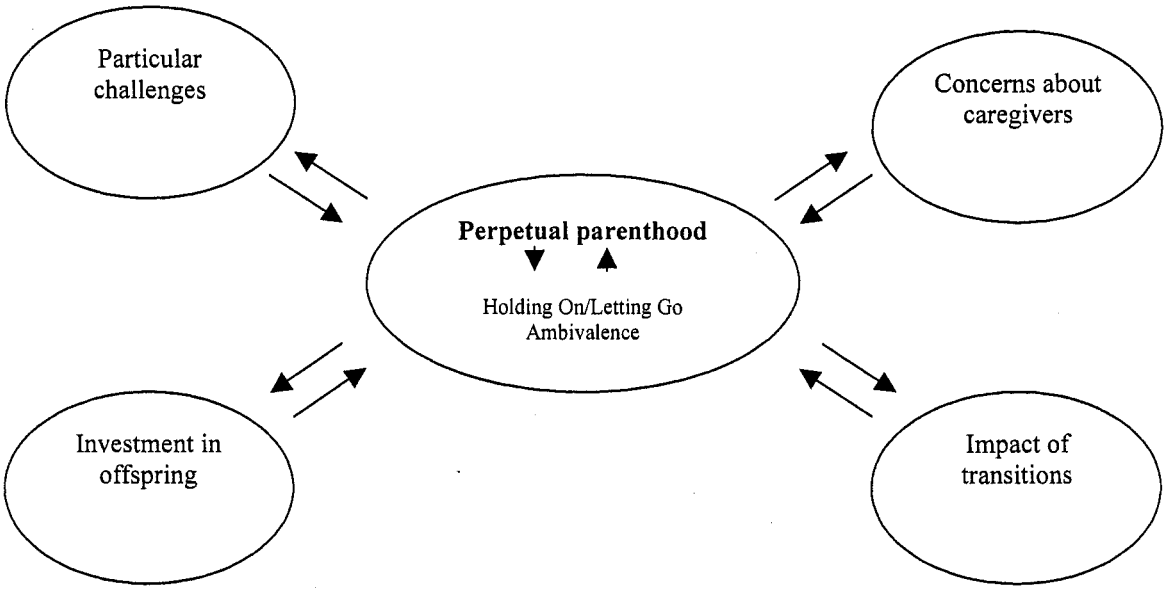

Figure 3. A diagrammatic representation of the organising concept of perpetual parenthood with the associated holding on/letting go ambivalence, and the correlation of identified themes emerging from the data.

Particular Challenges

Participants expressed various emotions around the challenges they faced as parents of offspring with an intellectual disability. They were unanimous in their expressed fear of their offspring being abused. The fear existed for daughters and sons alike. Wendy related instances of verbal, physical and sexual abuse that Peter had suffered (1.11.21-27; 1.12.17-13.1; 2.49.27-50.8; 2.50.14-32). Paul described his dawning realisation that Henry might be abused in an institution (2.51.1-10). Julie and Hugo expressed their gratitude for a social worker's intervention to remove Maria from a potentially abusive environment (2.51.21-27). Arising out of the vulnerability of her daughter, Julie stated explicitly that protection was a significant dimension to her understanding of parenthood.

It was a continuing role for her. "You still have that feeling you're her protector... regardless of where she goes..." (1.18.17-21); "I'm very protective of Maria" (1.32.16). Recurrent dreams of their offspring being lost which several participants reported may have revealed the burden of responsibility that participants felt as parents toward their offspring, and their fears of not caring adequately for their daughters and sons (1.16.21-23; 1.17.17; 1.18.1-2). The various reactions of other people to Ursula appeared to intensify Vicky's sense of her role as parent and her ongoing need to protect Ursula (2.9.29-10.17).

The fear of abuse, concern about losing their offspring, and critical responses of others to their sons and daughters appeared to be factors that bolstered parents' sense of themselves as "parents for life." Parents' role of advocacy appeared to have evolved in response to these particular challenges. Julie and Hugo maintained that whether Maria remained in the family home or not, they were obliged to continue advocating for her (2.26.13-24). Wendy expressed concern over who would perform such a role for Peter when he was no longer living with them (2.26.26-28). It appeared that their offspring's need to have someone advocate on their behalf was another factor that reinforced participants enduring sense of their vocation as parents irrespective of whether their sons and daughters remained in the family home.

Concerns About Others' Ability to Offer Care

Amongst the participants there seemed to be resistance to delegating parental authority to other caregivers. It was another issue that may have had correlation to perpetual parenthood. Julie articulated sentiments of other group members, voicing that from a parent's perspective "no matter where that child goes, nobody can do for that child as the parents do" (1.19.26-29). She did modify this statement later in the group when she admitted that some others could do as well as they could as parents, only it was hard for her to understand that and accept it (1.32.21-22). Participants gave several examples of instances where their offspring had not received an adequate standard of care from caregivers: Julie informed the group of Maria's burns not being tended to after she had

coffee spilled on her at a day care centre (2.25. 5-30); Vicky disclosed the impact on Ursula of caregivers being excessively authoritarian (1.36.11-30); she recounted instances of not being informed of vehicle accidents that Ursula had been involved in (2.23.15-24.2), and of the lack of attention of caregivers (2.28.26-30); Wendy expressed her discontent with the care Peter received in a group home (1.39.9-23); and Hugo described the far from adequate care Maria received while in an institution (2.51.30-52.15). Participants' resistance to delegating parental authority was another theme consistent with the phenomenon of perpetual parenthood. It is important to note that Paul and Tina were more affirming than other participants of the care their son Henry received in a group home (1.37.3-18). Interestingly, Tina and Paul were the parents who were most articulate about the need to let go of offspring.

The impact on their offspring of changes in caregiving staff may have afforded further grounds for resisting delegation of their parental authority. Vicky told of how destabilising it was for Ursula (1.23.16-21; 1.24.7-8). Paul gave a similar account in his experience with Henry (1.23.30-1.24.1). Hugo and Wendy shared separately on the difficulty new staff experience in understanding the subtleties of their offspring, and how it impacted on the ability of their daughters and sons to relate to the staff (1.43.12-17; 2.26.32-27.3). Therefore, legitimate concerns over the adequacy of other caregiving options for their offspring, and the impact of changes in caregiving staff on their offspring are two further factors that appear to be consistent with perpetual parenthood.

Parents' Investment in Their Offspring

A recurrent theme across the three focus groups was the degree of parents' investment in their offspring with an intellectual disability. It was evident through the childhood stories they recounted, in their expressions of devotion to their offspring and in the intimate knowledge of their daughters and sons they demonstrated. It was another theme that was consistent with the organising concept of perpetual parenthood.

All of the parents at some point over the course of the three focus groups spent time recounting childhood stories of their offspring, and in particular the challenges they discovered early in their parenting years. Their accounts revolved around diagnosis, early childhood skills training (and skills training in adolescent years in the case of Maria), and schooling. Amongst these parents it seemed that the trials they had faced served to strengthen the bonds with their children. Their sufferings and joys as parents had groomed them for special relationships with their children with disabilities.

Of the five parent dyads represented, three of the mothers verbalised their degree of commitment or devotion to their offspring with an intellectual disability. Vicky's investment in Ursula was such that she could not imagine her own life without Ursula's presence. There would be no reason for her to continue living (1.19.20-26). Her many years of primary caregiving for Ursula had brought an extraordinarily intimate knowledge of her daughter's body and being (1.32.32-33.18). Julie and Wendy both regarded their offspring with an intellectual disability as part of themselves (1.32.23, 25-26), Julie maintaining she could read Maria's mind (1.32.23). Wendy conceded that by reason of his disability, Peter's needs came before those of his other siblings (1.15.11-19). Julie expressed how much more difficult she found it to launch Maria from the family home than her other natural children (1.42.11-22).

Parents had grown to have a privileged understanding of their children given the longitudinal history of their relationship. Julie and Hugo at various stages over the two groups related Maria's means of communicating with them despite being non-verbal (1.31.1-8; 1.35.12-14; 1.42.30-1.43.17; 2.35.27-36.1). Paul and Tina showed particular understanding of Henry's personal rhythms (1.22.3-11). Vicky described her amazement at Ursula's comprehension of her father's death (2.19.1-18).

These three aspects (childhood stories, their expressions of devotion, and their intimate knowledge) demonstrated parents' investment in their offspring. It was an investment that appeared to bear a relationship to the suggested phenomenon of perpetual parenthood.

Impact of Transitions or "Segues"

The number and the intensity of the *segues*[179] in the life cycle of the family with offspring with an intellectual disability of which launching is but one instance may be consistent with a phenomenon of perpetual parenthood.[180] It can occur in different ways. Segue includes the movements from private school to public school; elementary schools to high school; self-contained classes to inclusion; school to work or workshop; family home to other residential setting (Hornstein, 1997). It can occur at different stages in the life of offspring depending on a number of factors that includes the offspring's eligibility for programmes or resources, the availability and suitability of programmes or resources, and the decisions of parents or other caregivers. It occurs with varying degrees of stability.

Amongst focus group members the transition from the family home to other residences (or launching as it is described in family systems literature) was relatively fluid in comparison to conventional families. There appeared to be more movement backwards and forwards between the various settings. Wendy described some of the inadequacies in Peter's living situation in a group house. He returned home every weekend "along with his laundry, and then we'd go back and fill up the refrigerator. We were still taking care

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[179] I have used the term *segue*. *Transitions* usually involve a critical moment accompanied by a transformation. There is a move from something old to something new. An example is the launching stage in conventional families. In families with an offspring with an intellectual disability, there are a number of incremental steps that I have named segues that cumulatively might constitute a transition. Nonetheless the segues differ existentially to what is understood by transition. The segues may not involve a critical moment and there may not be a move from something old to something new. In this way, the segues may more closely approximate the "tasks" that Carter & McGoldrick (1980, 1988, 1999a) associate with the different stages in the family life cycle. The segues are also of a different order to the "conflicts" that Erikson describes in his Life Cycle Theory. In each of Erikson's stages containing a particular conflict, there is a personality shift. Moreover, the epigenetic principle casts each stage as building on the previous ones. Adaptive resolution of one conflict provides the platform upon which successive conflicts are waged. A segue more closely resembles an incremental step than an existential shift in the conflated life cycles of the individual with a disability, the family and the intellectual disability itself.

[180] The term *launching* is not used with families with children with an intellectual disability amongst professionals in education in North America. In the US, the Individuals with Disabilities Education Act (IDEA) uses the term "transition," with particular reference to students receiving special education services from schools. The Beach Centre on Disability in Kansas on its webpage *Transition to adulthood overview* explains that "transition" refers to specialized planning and experiences to facilitate students' transition from school to adult life (http://www.beachcenter.org/). The transition planning process begins for any child receiving special education services and their families when the child turns 14 years of age. "Transition" is part of the curriculum for students with a disability. It is formulated to maximise students' opportunities for "integrated employment, independent living, social and recreational activities and full citizenship" as they move into adulthood.

of him" (1.41.3-4). They persevered with the arrangement for five years before welcoming him back into the family home. Tina and Paul received Henry back into their home for two months when caregiving staff went out on strike in the institution in which he was living (1.21.13-25). Julie and Hugh recounted how often Maria returned home in her first year in the residential Christian community (1.27.11-12). They remain deeply involved with Maria's life (2.34.26-27).

The data suggest that launching is merely one instance of a number of segues that parents negotiate with their offspring with an intellectual disability. The nature of segues themselves appears to differ from those occurring in conventional families. Segues in families dealing with intellectual disability require parents to be more flexible, with arrangements made for their offspring needing in some instances to be revisited. Segue remains an ambiguous term in itself, and it requires further clarification in family systems literature as has occurred with the term "transition" in the Individuals with Disabilities Education Act (IDEA) in the US.

Not only were segues of a different order to those occurring in conventional families, but they also appeared to be more stressful. Mothers reported varying degrees of emotional pain associated with the various transitions. Wendy recounted the stress and anxiety she experienced in Peter's transition from one school to another school and work setting, particularly with new transport arrangements (1.14.8-31). In the transition from the family home to another residential setting, all three mothers who had attempted to launch their offspring described their pain. Julie used the graphic metaphor of carrying buckets to catch the tears when the moving day came (1.26.23-31). Tina stated that letting go was "very, very hard... for me, especially" (1.1.24-31). Wendy recalled thinking to herself as she watched Peter on the day of his departure looking at his father, "this is really... this is bad stuff." She cried to herself all the way home in her car (1.40.15-22). It was evident that in some cases the pain still lingered. Even after five years of Maria living in a residential Christian community, Julie described her hurt in returning Maria to the community after time back in the family home (1.27.13-14).

Their identity as parents in perpetuity was evident to an extent in the guilt that some participants reported on their offspring leaving home. It seemed for some parents that to launch their offspring from the family home was bordering on irresponsibility. On the day Peter was to move from the family home to a group home, Wendy woke him and he muttered to her, "I was wishing this day would never come." (1.39.23-29). Wendy recalled the thoughts that crossed her mind. "What are you doing to this child? It is something he doesn't want." She reported similar feelings of guilt at a Faith and Light meeting when Peter moved at a later date into a residential Christian community. She clarified that she would have found it easier if Peter had said, "I hate you, and I cannot wait to get away from you" (field notes dated 26.04.03). Therefore, the nature and the frequency of segues that families encounter in the lives of their offspring with an intellectual disability, including their emotional impact on some of the parents, may have some bearing on a phenomenon of perpetual parenthood.

Summary

There were several themes that appeared to be consistent with the suggested phenomenon of perpetual parenthood The particular challenges that parents described (fear of their offspring's abuse, concern over losing them, and frustration and pain over others' denigrations of their daughters and sons), and the documented evidence of their concerns over others' ability to care for their offspring were factors emerging from the data that could be correlated with the phenomenon of being parents "for life." Furthermore parents' investment in their offspring (as evidenced through the childhood stories they recounted, in their expressions of devotion to their offspring and in their intimate knowledge of their daughters and sons), and the impact of transitions on parents, particularly the pain and guilt consequent upon their offspring's departure, were consistent with the organising concept of perpetual parenthood.

The Holding On and Letting Go Ambivalence

I have suggested perpetual parenthood as an organising concept that undergirds the identified themes emerging from the focus group discussions. One of the dialectics that all parents negotiate and renegotiate across the life of their offspring is their need to hold on to, and their need to let go of, their children. Parents of offspring with an intellectual disability will be no exception. While the perpetual nature of their vocation as parents, might suggest that the *holding on* pole is favoured, parents will negotiate a provisional resolution to the *holding on/letting go* ambivalence, which includes both poles. The two poles (holding on *and* letting go) vitalise each other. Therefore an important dimension of perpetual parenthood will be the provisional resolution to the holding on/letting go ambivalence that parents discover and create.

This concept of a central dialectic, dilemma or ambivalence in psychosocial development is one that Erikson proposed in his life cycle theory. Erikson's life cycle theory has contributed significantly to developmental psychology, positing eight psychosocial stages from infancy to old age. A tension or concern becomes central at each stage challenging one's world-view and self-understanding. The concomitant inner conflict necessitates making choices to resolve the tension between positive and negative impulses. Erikson describes these transition points as a "crisis."[181] Growth occurs through finding resolution, where the positive and negative impulses are held in creative tension or in a "favourable ratio."[182] One's own being and one's environment will influence how the balance is struck. This creative tension or synthesis produces the psychosocial gift or strength which makes up part of one's overall being (Whitehead & Whitehead, 1979, p. 30). It is important to note that Erikson's life cycle theory is not without its critics.[183]

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[181] "Crisis is used here in a developmental sense to connote not a threat of catastrophe, but a turning point, a crucial period of increased vulnerability and heightened potential" (Erikson, 1968, p. 96).

[182] The developmental conflicts particular to each stage are (a) basic trust vs. basic mistrust in infancy, (b) autonomy vs. shame and doubt in early childhood, (c) initiative vs. guilt in play age, (d) industry vs. inferiority in school age, (e) identity vs. identity confusion in adolescence, (f) intimacy vs. isolation in young adulthood, (g) generativity vs. stagnation in adulthood, and (h) integrity vs. despair in mature adulthood.

[183] Research psychologists struggle with the lack of scientific objectivity in Erikson's work, and his allusion to existential complexities which remain imprecise and untestable. On the other hand, one could view his work as interpretive rather than scientific, and assess it for coherence and comprehensiveness. Even from

Based on Erikson's understanding of the role of tensions, ambivalences or dialectics in the psychosocial development of human beings, it seems that a central ambivalence fundamental to the phenomenon of perpetual parenthood is that which arises between the impulse to hold on and the impulse to let go. There are four characteristics to the

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this perspective there are difficulties. Fitzpatrick (1976) points to flaws in Erikson's epigenetic theory. It tends to be reductionistic and Erikson's assumptions about the role of early experience influence what he sees and how he interprets it. It is a challenge to understand and communicate Erikson's formulations because they shift and are imprecise. Roland (1988, p. 314) observes that Erikson's theory has limited application in other cultures. The Indian and Japanese cultures do not place as much emphasis on autonomy, initiative and identity. They encourage dependency at an earlier age, and impose strict hierarchical family relations later on. Kotre (1984) argues that the demographic changes in Western society where people live longer and have fewer children necessitate a more flexible view of the life cycle. Pruyser (1976) also reacts against an invariant reading of the developmental stages. He states that "nothing is farther from the truth" than Erikson's psychosocial strengths being particular to certain age levels (p. 96). He believes the themes that Erikson raises are "perennial... relevant from the cradle to the grave, but their meanings and prominence and combinations vary in highly individual ways" (p.96). Like Kotre (1984), Pruyser (1976) suggests greater flexibility in viewing the themes, to allow for the reality that all people develop in different ways. The individual stages have also come in for criticism. Kotre (1984) argues that there is no evidence to support the claim that generativity is the dominant strength over a number of decades in adulthood. It is more likely to come to the fore at various "moments," depending upon circumstances. He identifies four different types of generativity: biological, parental, technical (teaching skills) and cultural (looking after a symbol system). A mother, for example, can experience biological generativity in young adulthood. Kotre (1984) claims that the impulse to generativity may also carry negative characteristics. Vaillant (1977) calls for an expansion to Erikson's stages, and sets about filling in what he regarded as "the uncharted period of development" which Erikson left "between the decades of the twenties and forties" (p. 202). Similarly more recent research identifies three or four different stages which may occur within Erikson's stage of mature adulthood. Browning (1973) notes how important the concept of care is to generativity. He argues that the current understanding of the term generativity "has degenerated into mere creativeness, experimentation, and inventiveness; it has become torn apart from that deeper capacity for care which completes and limits the truly generative impulse" (p. 164). Stern (1985, pp. 22-23) argues that it is the emerging cognitive and motor capacities of children and their ability to regulate social contact, rather than clinical issues such as trust or autonomy which influence their development. These clinical issues remain significant throughout the life cycle rather than being dominant at any particular stage. Stern (1985) questions the extent to which our adult personalities are shaped by the roles of our parents, and by the successful negotiation of various modalities (such as oral or anal). It may be that external factors play more of an influence than Erikson allows for. Yankelovich and Barrett (1970) note that it is difficult to appreciate the subtleties of Erikson's thought, given that he did not articulate his theoretical underpinnings. They argue that his subtle, ambiguous and all-embracing style fits the complexity of the phenomena that Erikson deals with. "Ego identity is the outcome of a complex interplay among biological heritage, the unfolding of individual potentialities, the responses of family and other significant persons, and the accumulated values of culture. None can be ignored if we are to capture the essential way in which a human being manages to become a whole and single person" (p. 134). Some writers from a feminist perspective have argued that Erikson has constructed his theory from a male perspective. Gilligan (1982) argues that for women the crisis of identity does not precede intimacy and generativity as Erikson suggests. "Intimacy goes along with identity, as the female comes to know herself as she is known, through her relationship with others" (p. 12). Even though Erikson (1968) recognises that the sequence is different for the female, "his chart of life-cycle stages remains unchanged... male experience continues to define his life-cycle conception" (Gilligan, 1982, p. 12). It is separation, or steps toward autonomy and independence, rather than intimacy that is the measure of growth in Erikson's theory (p. 98). Gilligan argues that it is intimacy which transforms adolescent identity struggles into the generativity of adult love and work (p. 164).

outworking of this dialectic in the lives of parents with offspring with an intellectual disability that require further discussion: (a) the dilemma is recurrent, (b) any resolution negotiated is provisional, (c) resolutions vary widely among families, and (d) both holding on and letting go have adaptive and maladaptive dimensions.

Recurrent

First, the phenomenon is recurrent. While the dilemma might typically be associated with the launching phase in the family life cycle, the data suggests that parents struggle to negotiate favourable ratios in the tension throughout the life cycle of their offspring with an intellectual disability. Parents reported various transitions that promoted the dilemma (such as attending school, changing schools, moving from a self-contained class to an inclusive one, shifting from school to work or workshop, leaving the family home).

Provisional

Second, a corollary to the recurrence of the dilemma is that any favourable ratio negotiated or discovered is provisional. The presence of another crisis may necessitate a reworking of the balance. Kegan (1982) proposed a psychosocial developmental schema depicting tensions between evolving dialectics in the form of a spiral or helix as opposed to a linear format. He posited each developmental stage as an "evolutionary truce" in the form of "a temporary solution to the lifelong tension between the yearnings for inclusion and distinctness" (p. 108). This model recognises that at each stage the balance struck is slightly imbalanced, which accounts for the provisional nature of each resolution, while also affirming the integrity of both desires for separation and attachment. The "evolutionary truce," in Kegan's (1982) terms, for these parents is a provisional or temporary resolution of the lifelong tension between clutching and releasing, holding on and letting go. The balance struck or received remains slightly imbalanced. It is this vulnerability, a state of minor disequilibrium that serves as an impetus for the family system to evolve.

Varied

Third, the provisional resolution of the dilemma will vary widely across families. It is important to respect the favourable ratio that a particular family in its particular context has negotiated. This ratio may differ not only from that of conventional families at a similar stage; it may also bear little resemblance to other families with an offspring at a similar age with a similar disability.

Balanced

Fourth, each pole of the dialectic, the yearning to hold on and the yearning to let go, has adaptive and maladaptive dimensions. It is important to respect the integrity of each pole. There may be an implicit bias in favouring one pole over another that reflects a cultural stereotype. For example in the attachment/separation paradox, Carol Gilligan (1982) identified the gender bias in prevalent developmental theories that preferred autonomy over inclusion, the former stereotypically identified as masculine, and the latter as feminine.[184] In a similar vein, there may be a sociocultural bias that associates holding on in families with emotional fusion, dependence and immaturity. There is a danger that letting go (a stereotypical male overemphasis) is promoted with language of growth and development, while holding on (a stereotypical female overemphasis) is devalued through the use of terms connoting dysfunction or pathology (Kegan, 1982). In situations where launching does not occur, or occurs in ways that may differ substantively from that which occurs in conventional families, is it fair to expect parents to let go? To let go of their offspring in a conventional understanding of the term may border on irresponsibility in their perception. It might seem like abandonment, and give rise to significant guilt. Perhaps parents rather than letting go of their offspring at the conventional launching phase may need to hold on to their role as parents and in some ways to expand it. It may

[184] Her critique has found wide acceptance. For example, Fulmer (1999) in a chapter titled "Becoming adult: leaving home and staying connected" observes that young adults experience pressure to individuate or separate from the influences of family and society. He believes that some of this pressure finds its source in autonomy-based theories of development as identified by Gilligan (1982). He advocates redressing the balance by emphasizing a continuing need for relatedness during this developmental phase (p. 216).

entail a revision of their self-understanding as parents and of their parental vocation, to accommodate further responsibilities.

Might it not be more appropriate to recognise and to value the integrity and the dignity of each yearning in this fundamental human ambivalence?[185] The data suggest that it is important for families to respect both dimensions of this universal existential dilemma in finding or creating the balance that works for them.[186] It is not a matter of repressing, denying or avoiding either polarity in order to accentuate the other. Rather, the paradox of the Gospel in which in crucifixion and resurrection are inexorably intertwined would hold that holding on and letting go are interdependent. Families negotiate and receive a provisional resolution in the preponderance of one polarity over the other.

I have suggested that the organising concept underlying the identified themes is the phenomenon of perpetual parenthood. An integral part of the phenomenon is the holding on/letting go existential ambivalence in the lives of these parents. The data portrayed the dilemma as recurrent, rendering any resolutions negotiated provisional. The data invited respect for the integrity of each of the fundamental yearnings of holding on and letting go, and demonstrated the idiosyncratic nature of the particular balances that different families construct and discover.

Relating the Concept of Perpetual Parenthood to Social Science Literature

In the foregoing section I outlined the organising concept emerging from the data of perpetual parenthood, integral to which is the outworking of the holding on/letting go dialectic. It is important to recall that the phenomenon of perpetual parenthood and the holding on/letting go ambivalence occurs within the relational context of the family. It is within this context that each family member experiences the phenomenon and the

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[185] It is worth noting that Bowen's (1978) model of self-differentiation does not advocate differentiation as individuality or independence but as a process of mature interdependence that balances distinctness with connectedness. In other words, both yearnings in the dialectic vitalise each other.

[186] By way of analogy, Beumer (1997) describes Nouwen's spiritual methodology as involving a movement between two opposing poles, "... alternating between extremes in order *to be found somewhere in the middle by the Eternal One*" (p. 141) [italics added]. Perhaps the balance finds the parents, as much as the parents find the balance.

dialectic, and interprets or ascribes meaning to them. In this section I explore how insights from the field of family systems theory may assist with explicating and interpreting perpetual parenthood from a systemic, developmental and a narrative/constructivist perspective. Clearly these are merely three perspectives in a field of knowledge that is multiperspectival. Furthermore, within the confines of this paper it is possible only to touch on selected ideas within each of these perspectives. I make no attempt to exhaust those systemic, developmental and narrative/constructivist themes that may be relevant to families with offspring with an intellectual disability in general, and to the concept of perpetual parenthood and the holding on/letting go ambivalence in particular.

A Systemic and Developmental Perspective

It is self-evident that the phenomenon of perpetual parenthood and any provisional resolution to the holding on/letting go dialectic occurs in the context of a family as it moves through the life cycles of individuals, the family and the intellectual disability itself. Parents may discover new dimensions to their vocation as parents. Families may need to reconfigure themselves at the various segues they encounter as they negotiate different ways of balancing holding on and letting go, a manifestation of the centripetal and centrifugal forces operative in any family constellation. While system theory holds that where one starts in addressing an issue in a family's life is immaterial, I have chosen to focus on the parents in the research as they constitute the executive team (in the case of a couple) that bears the responsibility for negotiating the changes. Nonetheless, how parents deal with the perpetual nature of their vocation, and how they negotiate a provisional resolution to the holding on/letting go dialectic will have repercussions across the various dimensions of the family. It will be a developmental and systemic process rather than a linear one.

Biophysical, psychosocial and spiritual-vocational dimensions.

VanKatwyk (1993, 2003) identifies three dimensions of family identity operative in the relational context of a family: the biophysical; the psychosocial; and the spiritual-vocational.[187] The outworking of the phenomenon of perpetual parenthood and the provisional resolution of the holding on/letting go tension will find expression in the family identity at each of these levels. At different phases in the family life, different dimensions may be in ascendancy. Where a daughter or son leaves the family home for another residential setting, in the initial stages parents may experience the departure in physical ways with significant grief or guilt. For example, Julie spoke of carrying buckets to catch the tears when Maria left (1.26.23-31). Tina stated that letting go was "very, very hard... for me, especially" (1.1.24-31). Wendy recalled thinking to herself as she watched Peter on the day of his departure looking at his father "this is really... this is bad stuff." At another stage, psychosocial phenomena may dominate, where parents both individually and collectively find themselves reworking their sense of who they are, and where they fit in, in the family picture and the world. It was clear that in Julie's reworking, she still saw herself as Maria's protector even after Maria was settled in a residential Christian community (1.18.17-21; 1.32.16). A third stage involves creating a revised story around their personal journey and their life as a couple and family to accommodate any new reality. I propose to enlarge upon this stage in the following section from a narrative/constructivist perspective. Suffice to say that Ursula's remaining at home with Vicky was so much part of Vicky's self-identity that she could not imagine her life without Ursula. "I don't want to live any longer, if I can't have her any more..." (1.19.20-26).

[187] The biophysical level as its name suggests is the lived reality of family life. The psychosocial environment of the family arises through members living in covenantal community with one another. It is the context in which members forge their own sense of identity. The spiritual-vocational dimension speaks to the distinctive place of each individual in the family (VanKatwyk, 2003, pp. 106-107).

Attachment theory.

Bowlby's attachment theory, founded in ethology, is a "primary organisational construct" to explicate essential human relationships (West & Sheldon-Keller, 1994, p. 4). It offers a developmental perspective. It posits that attachment in human beings is a type of "behavioural control system," where the system organises and directs behaviours corrected by feedback to achieve the set goal of safety and "felt security" (West & Sheldon-Keller, 1994, p. 12).[188] A threat to the security of the bond between children and their caregivers, produces proximity-seeking behaviours in the children.[189] Where children's proximity-seeking (i.e. attachment) behaviours receive an unsatisfactory caregiver response, children experience a double bind.[190] According to Bowlby, this phenomenon generates an insecure attachment, a defence mechanism in the attachment system. Patterns of insecure attachment evolve in order to prevent the threat of the loss of the security of the current attachment relationship.[191] All people occupy a position along the secure/insecure attachment continuum (1994, pp. 44-45).[192]

The attachment system involves both the proximity-seeking behaviours of the care-seeker and the complementary response of the caregiver. There can be wide variety in the congruence of the caregivers' response to the expressed needs of the care-seeker. The

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[188] "The function of attachment is protection from danger" (John Bowlby, personal communication, July 11, 1986; cited in West & Sheldon-Keller, 1994, p. 12). It is the acquiring of security rather than the controlling of primal urges that is the fundamental influence on personality development. The primary feedback information is the response of the caregiver; the primary danger is distance from the attachment figure. Bowlby (1958) distils his core proposition.

> It is my thesis that, as in the young of other species, there matures in the early months of life of the human infant a complex and nicely balanced equipment of instinctual responses, the function of which is to ensure that he obtains parental care sufficient for his survival. To this end the equipment includes responses which promote his close proximity to a parent and responses which evoke parental activity (p. 364; cited in West & Sheldon-Keller, 1994, p. 42).

[189] It is not so much the *loss*, nor even the *feared loss* of the relationship that is pivotal. It is the *feared loss of the security* invested in the relationship that activates proximity-seeking behaviours (1994, p. 81).

[190] The unsatisfactory response provokes further proximity-seeking behaviour (because of the threat to security) *and* an arrest of the proximity-seeking behaviour (because feedback information demonstrates that the particular behaviour does not produce the desired goal of proximity).

[191] As such, Stern (1985) maintains that lack of "affect attunement" to children can have as dramatic an effect on their development as an acute environmental trauma.

[192] Based on observation of the specific behaviours of infants that maintained proximity, re-established proximity, protested separation and demonstrated pleasure in reunion, Ainsworth (1978) identified four general attachment patterns: secure, avoidant, ambivalent and disorganised.

needs of their offspring with an intellectual disability may be such that no parent can respond to all their needs. Children with an intellectual disability may be more sensitive to any threat to the security of the attachment bond, and therefore there may be a lower threshold for the activation of proximity-seeking behaviours. It could amount to patterns of insecure attachment, which according to Bowlby form the template or inner representation[193] for future interaction with attachment figures.[194] Parents may be part of a system where their responses to proximity-seeking behaviours of their offspring continue to be perceived as unfavourable or unsatisfactory. The attachment system itself then exacerbates parents' sense of responsibility for their sons and daughters with an intellectual disability. They are kept in touch with the perceived inadequacy or the insufficiency of responses to extinguish the proximity-seeking behaviours of their offspring. Even if the attachment system does not collapse into run-away escalation,[195] the dynamics indicate that parents are caught in a complex web that is larger than themselves. Attachment theory would hold that from a systemic perspective parents of offspring with an intellectual disability might be more susceptible to holding on behaviours because of attachment behaviours in their offspring. This in turn reinforces the perception of the perpetual nature of their vocation. Systemic factors render the provisional resolution to the holding on/letting go ambivalence more complex than in conventional families.

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[193] Children develop an inner representational world or an "inner working model" based on their actual experiences of caregiver responsiveness. These earliest representations of attachment are carried forward and strongly influence relational patterns. Bowlby (1969/1982) acknowledges that significant events in adulthood may occasion a re-evaluation of one's working models. They may change as the result of interaction with new attachment figures. Nonetheless, inner representations factor prominently in shaping one's *modus operandi* of relating to others.

[194] Patterns of insecure attachment may also impact on the self-image of their offspring with an intellectual disability. Attachment theory holds that the caregivers' actual availability impacts on both children's expectations about the reliability of the attachment and their own self-concepts of their ability to evoke the desired response (West & Sheldon-Kelly, 1994, p. 51). It has cognitive and affective repercussions. A cluster of major emotions may become associated with insecure attachments, such as anger, guilt, anxiety or sadness.

[195] Bowlby maintains that activation of the attachment system suppresses other behavioural systems, rendering the use of other strategies (such as cognitive self-statements) to maintain "proximity" less effective.

Asymmetrical parent/child relations.

Boszormenyi-Nagy posits that relational ethics founded on trust and loyalty are fundamental to an understanding of family functioning.[196] His concept of the family ledger works with the entitlement and indebtedness of each family member. It recognises that parent-child relations are inherently asymmetrical. Children's entitlement is greater than their indebtedness simply by reason of their being members of a future generation (Boszormenyi-Nagy & Krasner, 1986). Repayment or compensation occurs through what children contribute to their own offspring and/or through fair and just actions in the wider community, which is a source of entitlement for the individual and for the parents. The question remains, What occurs in the situation where children are not able to repay parents, will never parent their own children, and will be unlikely to promote actively justice and fairness in society? Participants were highly invested in their offspring with an intellectual disability. Clearly, their offspring's entitlement is greater than their indebtedness in their early years. Does this imbalance continue throughout the lifespan of their offspring with disabilities? Or do parents see that there is a redressing of the balance, whether explicit or implicit, over the course of their offspring's lives?

Parents did not raise the issue of unfairness regarding the asymmetric nature of their relationship with their offspring. There were not responses that indicated a sense of "destructive entitlement" in Boszormenyi-Nagy's terms. Nonetheless, the fact that it is unlikely that there will be a rebalancing of the asymmetry of the parent/offspring with an intellectual disability relationship, reinforces parents' perception of the perpetual nature of their vocation. It will impact upon the provisional balance parents strike in the holding on/letting go dilemma. It need be noted that parents may experience repayment or compensation from their offspring through means other than those occurring in conventional families. Even though the asymmetry of the parent-child relationship

[196] His thought underpins the contextual school of family therapy.

> The essence of [contextual] therapy is... to help people achieve balance, a kind of harmony, in their closest and most important relationships. Those who lack the strength to state their own side, to stake a claim and defend it... are helped to shift towards being more willing to ask for what they want, perhaps to demanding it, and to accepting it from others. Those who are unable to appreciate other people's experiences, feeling, and needs, those who lack consideration for others, are helped along the path of greater sensitivity to others (Goldenthal, 1996, pp. 27-29).

persisted for Vicky and her adult daughter Ursula, Vicky spoke passionately of Ursula's vital role in her own life.

> *Vicky* ... but I cannot imagine my life without her [Ursula]... there's no reason for living for me. I've nobody else. I don't want to live any longer, if I can't have her any more... (1.19.20-26).

A Constructivist and Narrative Perspective

The processes of coming to terms with perpetual parenthood and of discovering and creating a provisional resolution to the holding on/letting go dilemma are cognitive as well as emotional. From a constructivist perspective, parents working through the phenomenon of perpetual parenthood and the holding on/letting go ambivalence may need to resituate themselves in a world that no longer looks as it once might have. This may entail reformulating their view of themselves, their view of their vocation as parents, and their worldview, as they create and discover new meanings for themselves. Therefore, reinterpretation is an essential part of working with parents who are experiencing challenges.[197] Parents generate new meanings and in turn discover and create transformed personal and family narratives. It provokes third-order change, a shift in orientation or perspective. The family is transformed because the parents as executives of the system situate themselves in the world differently with a reorientation of some of their core beliefs.

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[197] Pastoral theologian Charles Gerkin (1984) reflects on Boisen's metaphor of the "living human document" and the dimension of meaning-making.

> ... Boisen was fundamentally correct in his placing of the crux of human suffering at the point of the connection between experience and idea, between the occurrence of events and a language of meaning for those events. It is when that connection becomes blocked, distorted, or made impossible that the troubled person must seek a helper, an interpreter who may offer a new possibility of meaning (p. 53).

Gerkin emphasises the interpretive role that the carer provides in the pastoral care and counselling relationship. While I agree with the importance of this dimension, I see it as part of a broader package that the carer offers. The pastoral carer holds out implicitly any and all of those theological and ecclesial resources embodied in the local and visible faith community that might benefit the recipient of care.

Narrative theory.

It is a constructivist process *and* a narrative process. The data from the focus groups provided understanding on how parents construct their experiences and on the experiences themselves. Participants predominantly used stories to transmit and to illustrate their experiences. Narrative theory[198] holds that stories both shape how people interpret their experiences, and how people are formed by their experiences. People construct and discover their realities in the meaning-making dimension of their being through story and the story in turn constructs the realities by which people live. Narrative theory locates parents' stories in the context of the other stories by which their families, their religious communities, their society and culture organize themselves.[199] Stories blending word and action are the media by which parents make sense of their permanent vocation as parents, and negotiate the holding on/letting go dilemma.

Parents may need to *re-story* their understanding of their vocation as parents, and of the holding on/letting go ambivalence.[200] Paul and Tina discovered and constructed a revised understanding of their parental vocation when Henry departed the family home. They acknowledged that Henry could not remain at home indefinitely and that the longer he remained at home the more difficult it would be for him to leave.

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[198] Ricoeur's narrative theory holds that people discover and construct their sense of identity, their self-sameness over time, by collecting their experiences into personal narratives. People's thoughts and feelings, their sensory perceptions, their experiences and their relationships are "emplotted" or mapped on to a continuing story line or "narrative identity" (Ricoeur, 1988, p. 246). People become the authors of their own narrative identities in the way that a novelist creates a work of historical fiction. They construct a narrative text from their world of personal experience. The process is circular or recursive for as people read or perform their narrative identities they construct their world of experiences. It is important to recognize that although narration implies language and text, narration and narrative identity embraces all forms of human expression. People narrate with their beings not simply with words. See White and Epston (1990). I acknowledge my indebtedness to Dr. Lorne Mitchell (2000, p. 51) for the reference and the explanation. Dr. Mitchell (2000) presents the human relationship as a process of connecting through mutual narrating of self-texts. Meaning is generated or "performed" through the mutual narration.

[199] Stories can occur at many different levels: people carry their personal inner stories; stories are shared between people across time and space; families construct stories; and religious communities, societies and cultures use stories to express themselves (Anderson & Worthen, 1997, p. 3).

[200] VanKatywk (2000) describes the process of narrative spiritual care. "Narrative spiritual care attends to the stories of suffering by focusing on signals of the courage to live... Spiritual care with couples attends to the 'courage to be' edge in the marital resolution" (pp. 101-102). Similarly, in working with parents with offspring with an intellectual disability, narrative spiritual care might identify and punctuate accounts of *courageous* parenting experiences.

> *Tina* ... The younger they are [when leaving home], the easier they can adapt...
> *Paul* ... You know that someday you have to let go. And the older they get, the harder it is going to be (1.20.18-23).

For Tina, another facet of re-storying her understanding of the holding on/letting go dilemma she faced as a mother was affirming the gifts that others could bring to her son.

> *Tina* ... But at the same time, I feel that our son, might have become more independent, that he can get something out of other people, because everybody is different. He can learn something, and that's my way of letting go. We think that other people can do good... (1.20.9-12).

In a similar vein, a mother in a private interview reported that a turning point for her had come when she was able to recast her self-understanding as a parent. It had helped her to hear that her husband and she must have had special gifts as parents to be "given" a son with multiple disabilities. It was the beginning of a long journey of making a shift from reacting negatively to her son to recognizing his presence as a gift. Her re-storying included the recognition that by not allowing others to care for her son she was denying them the gift of his presence (personal communication, September 25, 2002).

Deconstructing and reconstructing illusions.

One of the tasks involved in re-storying is to deconstruct those illusions that may be impeding reality from emerging. VanKatwyk (2000) advances the premise that when a child introduces intellectual disability on to the family stage, the conjugal myth of the "ideal child" (the inner child of the couple) is shaken. The parent-ideal child relationship carries the dreams of the couple. Rather than diverting parents' gaze from their personal woundedness that their conjugal myth is seeking to rewrite, children with an intellectual disability force parents' vulnerability as individuals and as a couple back to centre stage. Perhaps in some ways children with an intellectual disability gift the family with the loss of the ideal child, which facilitates the finding of the real child (cf. Lk. 2.46). The incontrovertible presence of intellectual disability means there is less of the ideal in their offspring to be deconstructed so that the real can emerge. That is on the one hand. On the other, offspring with an intellectual disability risk being regarded as eternal children,

reinforcing the concept of perpetual parenthood. They spare their parents the anxiety of having to lose their children.

It was clear from the data that some of the parents underwent a process of dis-illusionment as the nature and the degree of their offspring's disability became apparent. Wendy for example spoke of the dawning realization that Peter had an intellectual disability when he was about three months old.

> *Wendy* ... I didn't think he [her husband Jack] could accept it. And I couldn't accept it either, because what I had feared seemed to be staring me in the face now. So I had to go at it slowly, and so little by little, I'd get the book out, and then read a little bit more, and a little bit more, and I showed it to my husband, and he didn't accept it... (1.9.11-15).

At the same time, there was evidence that for some parents their offspring remained "babies" or "children" even though they were clearly adults. Vicky recounted that she continued to refer to Ursula as " ... 'baby'... 'giant baby'..." (2.9.17). Wendy agreed. "We still *see them that way* [as children], but they're not children any more..." (2.9.9).

The data supported a *dis-illusioning* movement that occurred for some parents early in the offspring's life with the rapid demise of the conjugal ideal child. Conversely, there seemed to be a movement in the opposite direction later in their offspring's lives, where some parents viewed their mature sons and daughters with an intellectual disability, not as adults but as eternal children, unable to assume full responsibility for themselves. It might amount to the reconstruction of an illusion. The extent to which either of these movements influences the phenomenon of perpetual parenthood or the outcome of the holding on/letting go ambivalence is an area for further research.

Grief Theory from a Systemic and Constructivist Perspective

In Chapter Four I outlined aspects of grief theory from a systemic/constructivist perspective. I propose to explore what light these insights might shed on the phenomenon of perpetual parenthood and the associated holding on/letting go ambivalence. Grief theory would hold that the process of adjusting to the permanent nature of the parental

vocation is primarily *active* before it is passive, engaging all family members, including parents. It is a process which may require change in routines and even in life direction. It demands physical energy; members may experience and express considerable emotion; changes occur in relationships; and there is the work of finding new meaning in life and in one's own identity (Attig, 1996, p. 55). The data did confirm that coming to terms with their responsibilities occasioned the development and employment of resources of which parents might not have been previously aware. Hugo alluded to the enormity of the task that Julie and he faced in welcoming Maria after she had spent 14 years in an institution. The challenge they faced called forth new gifts.

> *Hugo* We took fourteen years in an institution, and tried to make it a home. Yes, it was a study. It was an awful big task. We had to do a lot of improvisation to adapt to make sure she did... (1.25.14-20).

Grief theory from a systemic perspective would hold that each family member with his or her own place and role within the family would have a personal and unique response to offspring leaving home. The research project focused on the response of parents and did not include offspring with an intellectual disability nor their siblings. Individual differences within the parental dyad were evident from the data. For Julie, Maria's leaving the family home was more painful than the departures of her other children. "... But hers [Maria's] was the worst, because she cannot talk or deal for herself..." (1.42.21-22). On the other hand for Hugo, the more challenging passage had come several years earlier.

> *Hugo* The two worst parts of what you call separation was when the province came back and said she was 18 years old, she was no longer a ward of the province. She was a child of God. Nobody could back up on nothing, not even the organisation that she was under (1.25.20-24).

Tina recognised that Henry's move to another a residential setting affected her more than it affected her husband. "Oh, it was hard, very hard... for me especially..." (1.1.24-31).

Amongst each of the couples represented in the group, it appeared that mothers found their offspring leaving home particularly challenging emotionally. In some instances it seemed important that the couple arrived at a shared understanding of the leave-taking. Wendy and her husband had agreed to allow Peter to move into a group home and to

evaluate its suitability for him as he went. "... But we said, 'Well, give it a try, see how it's like.' So he went along with it, and we went along with it..." (1.40.7-8). Tina and Peter had consulted together and had found a common rationale in moving Henry out of the family home.

> *Tina* ... The younger they are, the easier they can adapt...
> *Paul* ... You know that someday you have to let go. And the older they get, the harder it is going to be (1.20.18-23).

They agreed on the importance of trust in being able to "let go" Henry, and they were united in their need for clear boundaries regarding the nature and frequency of visits when Henry returned to the family home (1.27.28- 28.12).

A remaining contribution of contemporary grief theory from a systemic/constructivist perspective to the concept of perpetual parenthood is the notion of parents *relocating* relationships with their offspring rather than letting go. Traditional grief theories emphasised the need to relinquish one's ties to the deceased and to reinvest in relationships with the living. Relocation is a concept in contemporary grief theories that describes the re-ordering of one's relationship with deceased loved ones to reflect their continuing presence in one's own life and the life of the family, *and* their physical absence. Renegotiating the relationship takes place in such a way that the ongoing relationship with the deceased does not impinge upon one's ability to live meaningfully in the present. It seemed from the data that the concept of relocation might be a better term than letting go to capture what occurs between parents and their offspring. In all likelihood there will be no rebalancing of the asymmetrical relationship with their children. Adaptive parenting for these parents is not so much about letting go their offspring as it is about redefining their identity as permanent parents and renegotiating their parental relationship with their offspring with an intellectual disability. If the offspring leaves the family home, parents revise their relationships with their daughter or son rather than relinquishing them.

It was clear from Julie and Hugo that they still regarded Maria as part of them even though she has been living in a residential community for five years. "Oh, yeah... she's

still mine, she's still part of us..." (1.18.8); "... She's part of me... she's ours" (1.32.23). Wendy acknowledged that she still regarded Peter as part of herself (1.32.25-26). He had grabbed her heart as a mother (1.32.30). It might be that one of the tasks of perpetual parenthood for parents is the relocation of their relationships with their adult offspring with an intellectual disability, rather than letting go their relationships. Whether or not offspring with an intellectual disability remain in the family home, parents can engage in the task of relocating or renegotiating their relationships with them rather than struggling to relinquish them.

A Pastoral Theological Perspective

Anderson and Mitchell (1993) examine the process of leaving home from a pastoral theological perspective. They frame leaving home as a "religious task,"[201] a lifelong process involving both leaving and letting go, and through which one's gifts are discovered (p. 9). Their observations pertain to leaving home generally, rather than to the specific situation of offspring with an intellectual disability leaving the family home. Nonetheless, they represent a strong example of how one might understand the launching phase from a pastoral theological perspective. I suspect their observations are based on anecdotal evidence rather than empirical evidence. Some of their ideas may be purely speculative. My purpose in outlining some of their key ideas and relating them to the data is to offer a comparative perspective to that deriving from the social sciences discussed above.

First, they argue that leaving home needs to be balanced with being home. They posit that one cannot be at home unless one has left home.[202]"Paradoxically, our freedom to return home is a sign that we have successfully left home" (p. 22). Similarly, leaving home is

[201] They describe leaving home as a "religious" act in that it involves transcendence, as an "ethical" act in that it implies vocation or discipleship, and as a "sacramental" act in that it invites reconciliation (p. 134).
[202] This probably only makes sense where one affirms the role of paradox in pastoral theology. "From a pastoral theological point of view, paradox is the constant condition of human life in God" (p. 17).

not an end in itself. "We leave home so that we can go home again" (p. 146).[203] While it is difficult to know how one would test this thesis empirically, it resonates with the concept of a holding on/letting go ambivalence in parents of offspring with an intellectual disability. Perhaps it supports the idea implicit in the ambivalence that each pole in the dialectic vitalizes the other. The data confirmed the importance of seeing leaving home as one side of the being home/leaving home developmental metaphor (p. 27). There are times of staying as well as of going, times of "homesteading" as well as of times of journey.[204] Of the five offspring represented by the six participants, Henry was living in a group home, Maria was in a residential Christian community, while Peter, Ursula and Cassie (Kevin and Frances' daughter) remained at home. Wendy and her husband have since moved Peter into a residential Christian community. The temptation might be to pathologise those families where the daughter or son remains in the family home and to favour those families who have placed successfully their offspring in another residential setting. It is probably fairer to assess the functionality of living arrangements for offspring with an intellectual disability on a case by case basis.

Second, Anderson and Mitchell link a family's ability to negotiate the transition phase adaptively with its ability to grieve adaptively. A family's capacity to grieve and respond to change will influence the leaving-home process (p. 68). Furthermore, they argue that the family's inability to grieve is the major impediment to leaving home (p. 98).[205] This project did not set out to explore, let alone test the correlation between a family's capacity to launch their offspring and its ability to grieve (assuming both variables were

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[203] VanKatwyk (2000) reaffirms the concept when he states that welcoming children into a family is preparing for them to depart,

> Paradoxically, leaving home paves the way to come home and to be truly *at home* with each other. The story of the prodigal illustrates that more is lost when children stay at home. When children never leave home, whether physically or emotionally, parents are the ones who end up feeling lost, not able to find themselves in lives that carry them forward (p. 101).

[204] "Since home is where we start from, leaving home needs the parallel image of being home in order to express in the fullest possible sense our personal and social experience of human life" (p. 27).

[205] It was a point that Anderson and Mitchell (1993) reiterated. "A family's capacity to grieve its anticipated – as well as its unanticipated – losses will in large measure determine its ability to live through the crises of change" (p. 13). "How a family grieves for the losses that accompany change will enhance or impede the process of leaving home" (p. 89). "The capacity to adapt *to* change, particularly when it is unwelcome, enables a family to be a context *for* change" (p. 90). "A family's well-being depends in large measure on its ability to grieve both the expected and unexpected changes that must and will occur throughout its history" (p. 98).

amenable to analysis). It is clear that in the case of an offspring with an intellectual disability that there will be a number of other factors that impinge upon the decision to leave home which would not be operative in a conventional family. The parents of the three offspring who had left the family home (in Peter's case it was for a period of five years before returning) had experienced considerable grief. Nonetheless, it is a thesis that would require further exploration in the situation of families of offspring with an intellectual disability.

The third point that Anderson and Mitchell make is that leaving home is an inevitable phase in family life, rather than necessarily being a developmental stage in an individual's life. They see the whole family being involved in leave-taking, the actual leave-taking process differing for each daughter or son, and the family reconfiguring with each departure. They maintain that the timing often depends not so much on the departing offspring's "psychological readiness to separate" but on external events the family selects (p. 69).[206] While the data support their contention that leaving home impacts the whole family, and that the process differs for each child, it seemed that the psychological readiness of offspring with an intellectual disability was a factor that some parents weighed in making decisions about other living arrangements. For example, after the first attempt to move Henry into a group home did not succeed, and he ended up in a psychiatric hospital for 18 months (1.21.29-31), the support service recognised the importance of working with Henry's personal rhythms.

> *Paul* ... And we were not sure whether [the support service] would want to try it again, but [they] said, "This time we do it when he's ready." The first time they said, "That date" (November 22 or whatever), "that's the day he's going to move." But Henry |
> *Hugo* He wasn't ready |
> *Paul* No, he wasn't ready. So the next time they really took him a couple of times there, they visit and feel around how he reacted... (1.22.3-11).

Wendy reported that it was Peter's depression that precipitated his move into a group home based on the advice of an interdisciplinary consultation team for families with

[206] They propose two movements involved in the process of leaving home: the first concerns those leaving and their development of sufficient personal autonomy to return home again; the second is about the family, its ability to let go, and to respond both to the changes that have occurred as a consequence of the departure, and to those that will continue to occur (p. 88).

offspring with a disability (1.38.25-39.4). It proved to be an unsatisfactory arrangement. Nonetheless, the decision to leave home was based more on an assessment of Peter's personal situation than it was on external events.[207]

Finally, Anderson and Mitchell outline impediments to successful leave-taking and describe those elements they see in an adaptive transition. Potential obstructions occur when the leave-taking involves loss of a significant role in the family, when the family experiences the grief as overwhelming, when family boundaries are blurred, when parents fear being left alone, and finally, when parents do not farewell their children with blessing (pp. 99-106). They reiterate that the success of the leave-taking depends on a family's ability to cope with change. The adaptive leaving home process involves several key elements: first, being aware of the change as it happens, and the consequences for the family system of the change; second, grieving the loss; and third, being open to the adventure that the change offers (pp. 131-133). Based on the factors mentioned by Anderson and Mitchell, families with offspring with an intellectual disability may experience more barriers to successful leave-taking than conventional families. The extent to which the stated factors do exist in these families and the influence they have on launching offspring is an area for further research.

The Use of Ritual

Following up on Anderson and Mitchell's argument that parental blessing impacts upon leave taking, I conclude this section with a reflection on the place of ritual in transition from the family home to another residential setting in families with offspring with an intellectual disability. Family rituals both mark and make changes in families.[208] They

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[207] Anderson and Mitchell's contention that leaving home is another step in the process of formation of self that begins at birth could extend to offspring with an intellectual disability (p. 40). What is more difficult to maintain with these offspring is the idea that remaining at home necessarily entails a "diminished self." Could not their sense of self continue to evolve while living in their family home? Perhaps this is where Faith and Light can provide an opportunity for people with an intellectual disability. Whether or not they are in the family home, the Faith and Light community offers them a forum in which they can identify and express their gifts, and develop nurturing friendships.

[208] Imber-Black, Roberts and Whiting (1988), Imber-Black (1991), Imber-Black and Roberts (1992), and Wolin and Bennett (1984) outline how clinicians can make use of family ritual in their work. They divide rituals into four categories: (a) daily routines which punctuate the mundane activities of the family; (b)

contribute to a family's sense of identity, and its development of rules, boundaries and roles. Imber-Black and Roberts (1993) identify the various functions of ritual. Rituals define family membership and identity, bring healing in situations of loss, give expression to family beliefs and values and allow families to celebrate life. Significantly, rituals can be a means of changing the stories families tell about themselves, and the stories that others tell about them. Rituals can connect families to broader communities of support (Imber-Black, 1999, pp. 202-203).

Imber-Black (1999) maintains that families of offspring with an intellectual disability are at risk of developing symptoms with the combination of lack of social support, of challenging interactions with surrounding systems and institutions, of a sense of stigma and shame, of secrecy, and of isolation from family of origin and social networks. The lack of rituals to mark normative life cycle transitions may serve to reinforce the symptoms. Therefore, she advocates the role of ritual in bringing about systemic change.[209]

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family traditions which include birthdays, anniversaries, reunions and annual holidays; (c) celebrations both civic and religious which link the family with the identity of larger groups; (d) life cycle rituals which include both normative and non-normative nodal points. More recently, Imber-Black (1999, p. 207) has simplified the classification: transition rituals, healing rituals, and identity redefinition rituals. Transition rituals or life cycle rituals marking normative or non-normative nodal points are relevant for the purposes of the present study.

[209] Imber-Black (1999, pp. 207-209) gives an account of a moving transition ritual, where family members offered a gift (of something they owned or had made) to Karen (22) with severe developmental disabilities, as she moved out of the family home into a group home. Karen also offered a gift to each member of her family. Family members were not permitted to discuss their choice of gifts with one another prior to the ritual. The ritual was simple with few words spoken other than "thank you." Family members explained the significance of their gifts afterwards. The ritual confirmed the process of separation and continuing connectedness that was already in progress. It emphasized the mutuality or reciprocity of relationship that each family member had with Karen. It affirmed the individuality of each family member and the dyadic (as opposed to triadic) nature of each family member's relationship with Karen. It reinforced the importance of each family member's contribution to the life of the family as a whole. The therapist in this instance fulfilled the role of celebrant in the ritual. It was an example of a transition ritual. Other rituals Imber-Black (1999) identifies are healing rituals and identity re-definition rituals. Healing rituals can be helpful for a family with offspring with an intellectual disability to process unresolved grief around the parents' loss of expectations and dreams for their child and for their family life. Identity redefinition rituals assist a family to dispense with the stigma it might experience, and to transform relationships between family members and between the family and its societal network. Imber-Black (1999) advocates innovative rituals for a family with offspring with an intellectual disability as a means of acknowledging and honouring difference in situations that are non-normative (p. 213).

It appears that there are a number of segues or steps that families with offspring with an intellectual disability encounter as they move through the family life cycle. A simple ritual may facilitate the negotiation of major steps such as leaving the family home. It may assist parents in revising their understanding of their parental vocation. Families can make use of aspects of normative life cycle rituals in creating rituals that are meaningful to its particular situation. Imber-Black (1999) maintains that use of rituals contributes to the adaptive negotiation of transitions in the family life cycle and to relationship health both within the family and between the family and its surrounding context. They can assist the family in reorienting itself in relation to the world.

Summary

This chapter focussed on the third avenue of enquiry in this research project: namely, the reported experience of member parents of a Faith and Light group around the launching phase in the family life cycle. The organising concept arising from the experiential world of the parents in relation to their offspring was the phenomenon of perpetual parenthood, integral to which was negotiation of the holding on/letting go ambivalence. I outlined issues emerging from the data that may contribute to the organising theme of perpetual parenthood: the challenges parents face, particularly around the threat of abuse and the need to advocate for their offspring; their concerns over the adequacy of care their offspring receive from caregivers and health care professionals; the impact of the various transitions across the life cycle for parents and offspring alike; and parents' investment in their offspring and their peculiar knowledge of them. I explored the universal existential ambivalence of holding on/letting go that accompanies perpetual parenthood, where each pole in the dilemma is vitalised by the presence of the other: holding on is affirmed in letting go, and letting go in holding on. It is a dilemma that parents return to across the life cycle of their family, rendering any resolution they discover and receive only provisional. The balance struck in the ambivalence varies from family to family.

In the second section of the chapter, my attention turned to systemic and constructivist theories from a social scientific paradigm that assisted with explicating the organising

concept of perpetual parenthood and the related issues. Parents dealt with the permanent nature of their vocation and the outworking of the holding on/letting go dialectic at biophysical, psychosocial and spiritual-vocational levels. Attachment theory set parents' responses in the broader context of a behavioural system, activated as they were by proximity-seeking behaviours. Boszormenyi-Nagy's concept of relational ethics drew attention to asymmetrical parent-child relations. Ricoeur's narrative theory offered a way in which parents can re-story their self-understanding as parents, their relationships and their world-view. Recent grief theory invited parents among other things to consider relocating rather than relinquishing ties. A pastoral theological perspective framed leaving home as a religious task. Finally, Imber-Black and others advocated the role of ritual in facilitating adaptive negotiation of the various transitions.

I stated in the introduction to this chapter that the data had divided the research question into two distinct parts (a) the experiential world of parents as they faced launching their offspring with an intellectual disability, and (b) the role of Faith and Light as a provider of pastoral care and counselling in that context. Having dealt with part (a) in this chapter, I turn to part (b) in the next chapter and explore what a theological pastoral care and counselling, the community of Faith and Light and the phenomenon of perpetual parenthood might have to offer each other.

Chapter Eight

INTERACTION OF THEOLOGICAL PASTORAL CARE AND COUNSELLING, FAITH AND LIGHT, AND PERPETUAL PARENTHOOD

At the beginning of the previous chapter, I outlined the three avenues of enquiry in this research paper (a) a theological pastoral care and counselling, (b) the defining features of Faith and Light, and (c) the concept of perpetual parenthood and the concomitant holding on/letting go ambivalence. In the previous chapter I addressed the phenomenon of perpetual parenthood, the organising concept that seemed to issue from the identified themes in the ethnographic study of parents in Faith and Light. In this chapter I explore how each of these three foci of study informs the others. What do a theological pastoral care and counselling, the community of Faith and Light, and the concept of perpetual parenthood have to say to one another? How might each contribute to an understanding of the others? What implications will each have for the others? I have chosen to organise the enquiry around three questions.

1. How do perpetual parenthood and Faith and Light inform each other?
2. How do perpetual parenthood and theological pastoral care and counselling inform each other?
3. How do theological pastoral care and counselling and Faith and Light inform each other?

The responses to these questions represent the implications of the findings of this research project.

Perpetual Parenthood and Faith and Light

In exploring how these entities inform each other, I begin with two potentially fruitful lines of enquiry. First, how *is* Faith and Light responding to the phenomenon of perpetual

parenthood based on parents' reports? Second, how *could* Faith and Light respond to the phenomenon based on parents' reports and the community's foundational literature?

How Is Faith and Light Responding to Perpetual Parenthood?

Participants turned to the topic of Faith and Light in the final third of the first focus group (1.51.9ff), and in the final third of the second group (1.40.13ff). This may have been attributable to the manner in which the researcher moderated the focus groups. When participants' attention did turn to Faith and Light, they generally spoke appreciatively and favourably of Faith and Light from their perspective as parents and from the perspective of their offspring. Some participants did identify where they sought changes in the community's life.

Parents' responses for themselves.

What were the themes that emerged as participants spoke of Faith and Light? From the parents' perspective, it was the psychosocial dimensions of the community life they most valued. Faith and Light afforded them a space where they felt supported. Wendy recounted her experience at a national meeting, where two men intervened on her behalf when her son Peter became upset during the mass (1.54.10-30).

> *Wendy* And I came away from that, I was on a high. I thought Faith and Light has got to be the best... because I felt so much support... for myself... And no one had ever given me support like that before... nobody... (1.54.27-30).

Tina and Paul described how they felt needed, and relied upon, at Faith and Light (1.55.17-18, 27-28). Hugo expressed how welcome he felt at each meeting (1.61.1-13, 64.3-4). For Tina, meeting together at Faith and Light gave her a greater sense of solidarity with the caregivers working with her son Henry (1.55.11-16). Hugo identified the interaction of Faith and Light, as its defining characteristic. "But the interaction, it's *it*... Definitely is..." (1.63.12). Wendy reiterated the significance of the dimension of friendship within the movement for parents as much as for their offspring. "Oh, it's wonderful to have the friends... Because parents need the friends as much as the others

do..." (1.53.32-54.10). It was a source of amazement for her that friends of her son would come to the meetings (2.47.22-23). Therefore, parents identified mutual support and understanding, welcome, interaction and friendship as those aspects of community life in Faith and Light that they appreciated.

Parents' responses for their offspring.

Parents spoke of ways in which their offspring with an intellectual disability benefited from Faith and Light on both psychosocial and spiritual-vocation dimensions. Faith and Light provided a non-judgmental atmosphere where their offspring could be listened to. Wendy described the ambiance of acceptance. "... But there's nobody there that judges them. Everybody loves them, and values them for who they are..." (1.53.3-4). She maintained in the second focus group that being listened to was something that their offspring valued (2.40.29-41.2). Hugo added later in the group that it showed acceptance (2.45.28-32). Vicky alluded to the friendships that her daughter Ursula had made in the community, and to the positive impact those relationships were having on her daughter's life.

> *Vicky* ... She's different, we feel that we see the same people.... I call them Faith and Light friends. [I say to her] "We go see our Faith and Light friends." She likes to sing and she likes to see everybody... Now she got a big grin and smile on her face... (1.48.20-28).

One of Faith and Light's principal gifts to their offspring was the way in which the movement revealed their gifts and called forth their beauty. Wendy expressed thoughts with which other members resonated. "... and I think Faith and Light helps us to see the beauty of each one of these people who have developmental handicaps" (1.51.32-51.1). She referred specifically to their gift of teaching, one which Vanier emphasizes. "... They're teaching us all the time. They're the teachers and we're the students" (1.52.27-28). Faith and Light provided a setting where their offspring could use their gifts and exercise their ministry to others (1.53.1-4). Julie added that it was a forum where their offspring could express themselves. "... These people [with disabilities] can express themselves in other ways even if they can't do it like us..." (1.53.22-23).

Hugo and Julie were the only participants who identified the role of Faith and Light in providing religious education for their offspring through the use of mime in particular.

> *Julie* ... Because if you just sit there and watch what's going on, those people are interacting with some of the skits you put on and some of the songs. There is an interaction and I really believe they know about... they've learned about God. The way some of the pictures are... it's more than pictures... it's people expressing themselves through pantomimes and singing... It's a beautiful concept that is going on in that short time (1.44.6-17).

She expressed a desire that more people "in the religion aspect of the community should spend a time at Faith and Light, to see what is going on..." (1.55.1-2).

From their perspective, parents focused on the psychosocial aspects of the Faith and Light community life in responding to their needs as perpetual parents: mutual support, understanding, interaction and friendship. For their offspring, they valued both psychosocial and spiritual-vocational attributes: listening, acceptance and friendship, together with revelation of their beauty, exercise of their gifts and growth in their spiritual life. The next question to consider is, How do these reported themes fit with what recognised authorities in the Faith and Light have identified as charisms of the movement? I propose to locate participants' responses within the broader context of the characteristics of the Faith and Light movement.

How Could Faith and Light Respond to Perpetual Parenthood?

I outlined some of the theological motifs and spiritual practice features of Faith and Light in Chapter Three. I propose to reacquaint the reader with some of the main points arising from the foundational literature before considering what Faith and Light might hold out to the concept of perpetual parenthood. The Charter and Constitution probably give the most comprehensive overview of Faith and Light's nature and activity. Jean Vanier, one of the co-founders of the movement[210] has written extensively on the spirituality and the mission of Faith and Light and L'Arche. Father Joseph Larsen, the International Chaplain

[210] The other co-founder is Marie-Helene Mathieu whose thought and action has been highly influential in the genesis and evolution of the movement. Unfortunately I did not have access to any of her writings on the spirituality of Faith and Light.

has summarised the way of life in Faith and Light. I turn to these sources in retracing briefly the contours of Faith and Light's theology and spirituality.

The Charter and the Constitution.

The Charter defines the spirit of Faith and Light and it is to be read with the Constitution (Prologue to the Constitution). The prologue to the Charter reads: "Faith and Light was born of a desire to help people with an intellectual disability and their families find a place within the Church and society." I summarise below some of the essential characteristics of the movement arising from its foundational documents.

- It is a lay Christian movement sourced in the life and teachings of Jesus Christ, with particular reference to the Beatitudes
- It is a community which evolved from, and is a response to, the suffering of parents and their offspring with an intellectual disability
- It acknowledges the capacity of people with an intellectual disability to reveal the person of Jesus Christ
- It is a community founded on relationships of faithful friendship among people with an intellectual disability, their families and their friends
- It emphasizes presence to one another in suffering and coming together in joy
- It affords recognition and respect to each person as created in the image of God and loved by God
- It calls each of its members to grow spiritually and to develop competencies
- It reveals and calls forth the beauty and the gifts of each person

  Gifts of people with an intellectual disability include their capacity for welcome, their simplicity and their tenderness
- It respects diversity and models inclusivity
- It emphasizes celebration and prayer in its corporate life
- It adopts an integrative stance towards faith communities and promotes collaboration with organizations in society
- It emphasizes communion and solidarity with other Faith and Light communities

Jean Vanier.

While there are clear differences between the Faith and Light and L'Arche movements (a fundamental one being that the latter finds expression in residential communities), their spiritualities are similar. Many of the dominant motifs that Jean Vanier traces in the spirituality of L'Arche will carry similar weight in a spirituality of Faith and Light. At the beginning of *The heart of L'Arche*, Vanier (1995) writes, "We in L'Arche are called to live in special way the mystery of the poverty and weakness of Jesus who came to be with the poor and the weak" (p. 15). Jesus *became* poor; he did not merely *serve* the poor. At the centre of Faith and Light is *mystery* – the mystery of the poverty and the vulnerability of God in Jesus Christ. It is a movement that is founded on suffering and is a place of suffering. Members of Faith and Light are called to reveal the face of Jesus Christ to others who are hurting.[211]

Members are not called to solve the problem of suffering, so much as they are to be *present* to the suffering of others, and therefore to their own suffering. Members are called to discover their own pain, and in so doing their need of one another. The impossibility of solving the pain and the helplessness people experience in their powerlessness brings people together. In coming together the community becomes the face of Christ. They are empowered to live what is impossible through Jesus' promise of his continuing presence (Mt. 28.20b). In the Spirit they begin their own process of transformation of being able to love more deeply (Jn 15.12).

Community life is essential to the movement, and is comprised of sharing daily life together made up of "little acts of love and service" (1995, p. 49). It means remaining "faithful to small things" (1995, p. 61). Community built through listening to one another and being present to one another's pain becomes a place of meeting each other rather than merely co-existing together. It emphasizes mutuality, reciprocity and commitment in relationships. It is a place of celebration and forgiveness. The movement embodies and

[211] Vanier, in an address entitled *The mission of Faith and Light* delivered on September 28, 2002 to the Faith and Light International General Meeting in Rome, commented that it was for this reason that he was not surprised that there were not more young people involved with Faith and Light and L'Arche.

models inclusivity, based upon the gifts of the vulnerable to call others to peace and to unity. It is a movement that emphasizes the body rather than words. It seeks to balance the contemplative and active dimensions of the spiritual life.

Vanier (2002) summarises the mission of Faith and Light. Members are called to enter places of pain, to welcome people in pain and to create community together. The movement espouses communion with God in Jesus Christ who is hidden in the hearts of the vulnerable. It is for this reason that Downey (1990) describes it as "a spirituality of the heart" (p. 199). It is a spirituality which believes in the "fundamental beauty of the human heart and its capacity for love" (Vanier, 1995, p. 65).

Father Joseph Larsen.

Faith and Light's current International Chaplain, an influential figure in articulating and guiding the spirituality of the movement,[212] identifies its two primary well-springs of life: "the Good News of a loving Father that Jesus has brought us and the ties of human friendship of which Jesus has given us an example" (J. Larsen, personal communication, September 24, 2002). Larsen (2002) outlines the two trajectories of its spirituality in the following statements.

1. All the members – parents, children, friends – acknowledge the suffering that is part of human life, and want to live it in abandonment to God the Father of Jesus Christ.
2. All the members – parents, children, friends – want to live the spirit of friendship as a message of God's love, following Jesus' example.

Abandonment (Jn. 19.25-27; Lk. 22.35, 42; 23.46; Phil. 2.5-11) finds practical expression in an explicit attitude of childlike dependence on God (Mk. 10.13-16; Ps. 131), in a

[212] An example of his guidance appears in his suggestions for *Deepening one's way of life in Faith and Light.* It involves reflecting intentionally on one's current way of life in Faith and Light and recommitting oneself to this manner of living. One chooses one of the aspects of life in Faith and Light that he lists, and calls to mind an experience, which relates to the aspect. Following this, one meditates on one of the Scriptural passages linked with the selected aspect. One shares any insights arising from the silent reflection on the text. The exercise may be done in groups or individually. It emphasises the contemplative dimension of the movement's vocation.

recognition of God's providence (Mt. 6.25-34), in a chosen lifestyle of simplicity (Mt. 8.20), and in cultivating presence to God through means such as pilgrimages (Lk. 2.41; Jn. 11.55-56).

Friendship (Jn. 11.33-36, 17.26; Mt. 11.19; Lk. 14.12-14) is the only support the movement purports to be able to offer for intellectual disability. Friendship reveals other's beauty and calls them to growth (1 Cor. 1.27; Jas. 2.5; Mt. 5.3). It forms the heart of the community life (Mk. 2.13-14; Jn. 15.14-15). It means that structures are collegial rather than hierarchical, with a lay leadership based on service in friendship, rather than domination (Mk. 10. 42-45). Chaplains are friends, called to reveal Jesus and the Church (Heb. 7.13-14). *Being with* rather than *doing for* is a fundamental expression of friendship (Lk. 10.39; Phil. 2.7-8)[213], emphasizing the physical dimension of being, and informing the nature of prayer (Mt. 6.7-8). Friendship fosters intimacy (Jn. 15.15), which dismantles barriers, invites forgiveness (Col. 3.12-14; Eph. 4.32) and generates spontaneity (Mt. 5.37). Spontaneity is a harbinger of personal freedom and joy (Lk. 6.22-23; Jn. 16.22; Phil. 3.1, 4.4; Lk. 10.21). Joy finds expression in celebration and shared meals (Mk. 2.19). Friendship is a building block of ecumenism (Jn. 17.20-23) and promotes fidelity and financial solidarity (2 Cor. 8.1-5). Friendship is Faith and Light's gift to the Church and to the world (Gal. 3.28). With the spiritual gifts that Faith and Light has been given, it is called to reach out to others (Acts 4.20).

In this way, Father Larsen sees the spirituality of Faith and Light settling upon the twin pillars of abandon to, or trust in God, and friendship. As one receives and appropriates the grace to trust God and to abandon oneself to God, one's heart radiates peace and friendship. Joy and intimacy are essential features of friendship. Trust in God and friendship are closely linked. The love of friendship is a manifestation of God's love and

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[213] The concept of "being with" is axiomatic to Father Larsen's understanding of his own vocation and the way of life of Faith and Light,

> Jesus' life "Emmanuel" that means "God with us"... [In] the Christological hymn in Philippians 2 you see him going down to be equal with us, so the "being with" is very much [evident] in his life, and friendship is the translation of it... in that sense Jesus life has helped me to find within friendship the way of "being with" and then you don't have to say much, you only have to "be with"... to "be with" is radiating the love of God who is also with us all the time...
> (J. Larsen, personal communication, September 27, 2002).

makes God present (cf. Jn. 15.15).[214] The love of friendship has implications beyond the community, bearing the potential to resolve conflict in the Church and in the world. [215]

This section in the chapter is teasing out how Faith and Light and perpetual parenthood inform each other. I have explored how Faith and Light *does* respond to the phenomenon based on parents' reported experience. Through this brief reflection on foundational literature of Faith and Light, I have sought to position the reader to be able to explore what other resources Faith and Light *could* offer parents in this situation.

Parents' responses.

From the outset, it appears that there is nothing that parents raised in their experience or in their offspring's experience of Faith and Light that does not appear in the foregoing review of the essential characteristics of Faith and Light.

Parents appreciated the community dimension of the movement. Julie captured a sentiment that other participants appeared to share. "... There is also a feeling of community when we have the lunch and that together..." (1.44.18-19). The word "Community" appears many times in the Charter.[216] Faith and Light expresses itself in

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[214] Father Larsen shares a prayer that for him epitomises the vocation of members of Faith and Light

> RADIATING CHRIST
> Dear Jesus, Help us to spread your fragrance everywhere we go. Flood our souls with your spirit and life. Penetrate and possess our whole being, so utterly, that our lives may only be a radiance of yours. Shine through us, and so be in us, that every soul we come in contact with may feel your presence in our soul. Let them look up and see no longer us but only Jesus! Stay with us, and then we shall begin to shine as you shine; so to shine as to be a light to others; the light, O Jesus will be all from you, none of it will be ours; it will be you, shining on others through us. Let us thus praise you in the way you love best by shining on those around us. Let us preach you without preaching, not by words but by our example, by the catching force, the sympathetic influence of what we do, the evident fullness of the love our hearts bear to you. **Amen**
> © Missionaries of Charity Fathers – Tijuana Mexico c/o Box 1959, Chula Vista CA 91912 USA

[215] Father Larsen sees a distinction between the movements of Faith and Light and L'Arche in this regard. L'Arche sources itself in, and incarnates the love of family; Faith and Light is grounded in, and lives the love of friendship. The reflections in this paragraph come from a private interview given on September 27 2002 at the Faith and Light International Conference in Rome.

[216] It appears in the opening sentence of the first section explicating the "Vocation of the movement." "Faith and Light is a *community* movement" (I, introduction). Each ensuing subsection affirms Faith and Light as a community movement: (1) a *community* which meets; (2) a *community* of fiesta and celebration; (3) a *community* of prayer; (4) a *community* of friendship and faithfulness; (5) a *community* for taking root

and through community. Parents specified the aspects of community life that they valued for themselves: mutual support and understanding, welcome, interaction and friendship. The Charter clarifies what it seeks to offer to parents.

> To the parents, Faith and Light gives support in their trials and helps them to better appreciate the inner beauty of their children. A number of them, in turn, become a source of strength and an assistance to other parents who are crushed by their suffering and their daily difficulties (I, Introduction).

From the perspective of these parents, it appears that Faith and Light provides the community life that it purports to embrace in its Charter.

From the perspective of their offspring, parents identified features of the way of life of Faith and Light that embraced psychosocial and spiritual-vocation dimensions of the being of their daughters and sons. They appreciated the way in which the movement revealed the beauty and giftedness of their offspring, facilitated personal growth and fostered friendships, offered a forum where they were accepted and listened to, and provided Christian formation for their offspring. Each of these features appeared in the overview of the characteristics of Faith and Light. The introduction to "The vocation of Faith and Light" appearing in the Charter states,

> Faith and Light gives to persons with an intellectual disability the possibility of recognising and using their gifts and discovering the joy of friendship.

Meetings provide "a time of getting together to talk and to listen to one another... Sharing in small groups enables each person to express him/herself through words or other forms of communication" (I, 1). The Charter recognises that in order to exercise their gifts and to grow as persons, people with an intellectual disability need to belong fully in Church and in society (I, 3). Personal growth is encouraged. While the role of Christian education is not mentioned explicitly in the Charter, it calls every member, "even the most disabled... to deepen his or her life in Jesus, to receive all the spiritual richness from his/her Church, sacraments, liturgical tradition, etc..." (II, 1). Hence, the

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and integrating. It is reiterated in the second section entitled "The inspiration of Faith and Light" where the second subsection bears the heading "The need for *community*." It is reaffirmed in the third section "Faith and Light activities," with the opening subsection labelled as "A *community* movement."

particular ways in which parents saw Faith and Light assisting their offspring all appear in the overview of Faith and Light's characteristics.

Parents did suggest changes to the format of the monthly meetings, to facilitate greater involvement of their offspring. Specifically they asked for more opportunity for their offspring to interact with others, and to share their news (2.40.29; 2.45.1-14; 2.46.24-25). They wondered whether their daughters and sons might benefit from more singing, and more activity with the singing (2.44.1-10). Wendy suggested greater informality in the gatherings, presumably for the sake of offspring. "... And I think you have to have more of that, more relaxed... and not so much structure..." (2.43.28-32). It seems that one way in which Faith and Light could respond to parents' needs, is by tailoring the format of the meetings to encourage and facilitate active participation of people with an intellectual disability wherever possible.

A second way in which a Faith and Light community could respond to perpetual parenthood is by providing facilitated groups where parents are able to share their experiences with other parents. It seemed that parents found the focus group format helpful, to the extent that one group member hosted a third group meeting in her own home. Meeting as a parent-specific group afforded a forum for members to share painful experiences (as occurred in the second focus group), and to provide practical information on resources available to them as parents of offspring with an intellectual disability. This aspect was evident particularly in the third focus group meeting (see for example 3.1.6-10; 3.1.17-20; 3.5.31-3.6.6; 3.36.27-3.37.23). It seemed parents' empathy was a resource, whether those parents had children with an intellectual disability or not.

> *Hugo* ... But by the same token if you could recruit other parents, they don't have to have handicap [handicapped children], but if you could convince them of what your needs are, because of the handicap, you're home free... You get two thirds of your problem solved... (3.10.2-6).

Faith and Light's charisms.

The enquiry now turns to those aspects of Faith and Light outlined in the overview, and not identified by parents themselves, which might assist them as they live perpetual parenthood The Charter, Jean Vanier and Father Larsen all emphasise that Faith and Light is not simply a community movement. The Charter defines it as a lay community movement[217] that has its roots firmly in Christian Scripture and Tradition.[218] Jean Vanier repeats that Faith and Light incarnates the mystery of the poverty and the vulnerability of God as revealed in Jesus Christ. This is the cornerstone of community life and activity. Fr. Joseph Larsen emphasises that the Gospel of Jesus Christ is foundational to the movement. The movement is explicitly Christian.

Parents identified interpersonal dynamics of Christian community that they appreciated for themselves in their lives as "perpetual parents": mutual support and understanding, welcome, interaction and friendship. These are embodied aspects of Christian corporate life. I wonder whether Faith and Light incarnates other dimensions of Christian Truth that may respond to parents' experience of their continuous vocation?

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[217] Its lay status was reaffirmed at the International General Meeting in 2002 with the amendment to the Constitution. Section II.3 now reads, "The community is coordinated by a leader. The leader is always a layperson" (3). Footnote (3) reads: "At each level of responsibility, the leader (coordinator or correspondent) is a layperson."

[218] The Charter emphasises that through friendship, made up of tenderness and fidelity, members become "signs of the love of God for one another" (I.1); that it is God "who calls us together and enables us to discover the covenant that unites us" (I.2); that "the personal meeting and celebration find their culmination in prayer, in union with God and the celebration of the Eucharist and/or other religious celebrations" (I.3); that "Communion in the cross prepares a resurrection in rediscovered brotherly love" (I.5); that members search for ways of worshipping together at community meetings, "united as brothers and sisters in Jesus Christ" (I.5). The inspiration for the movement arises from the truth that "every person, able-bodied or handicapped, is equally loved by God and that Jesus lives in them, even if the person concerned can barely express this" (II.1). Furthermore, all members are called to deepen their lives in Jesus and to become a source of grace for others (II.1). The Charter acknowledges that "It is only Jesus and his Holy Spirit who can transform our hearts to enable us to welcome the poor and rejected person..." (II.2). It is God who has given people with an intellectual disability their prophetic gifts of the heart (II.2). The source and the fulfilment of trusting friendships between members is Jesus Christ (III.1). God inspires a community's activities (III.2). The Constitution sets out that the International Association of Faith and Light is "to be a witness to the attitude of Jesus towards people with intellectual disabilities and to recognise them fully as children of God..." (Const. I.5)

"Presence" as a response to suffering.

Fundamental to an understanding of Faith and Light is the truth that it is founded on suffering and is a place of suffering.[219] Its response to suffering is *presence*: personal presence and divine presence. Frances Young compares and contrasts the theology of Faith and Light and liberation theologies. Both theologies embody hope for the underprivileged. Liberation theologies promote social action that empowers the marginalized. The theology of Faith and Light advocates *mutual* liberation through presence to one another.[220] Presence to one another, to oneself and to God in communion and in community is to Faith and Light what political activism is to liberation theologies.

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[219]Vanier has spoken repeatedly of the central place of suffering in the inception and the continuing life of Faith and Light. To deny or ignore its reality is to fail to understand the movement. Faith and Light does not purport to remove the pain, or to solve the situation that gave rise to it. It calls its members to be willing to enter into a world of suffering. It invites them to be *present* to the suffering of another, which requires that members learn to be present to their own pain. Vanier maintains that suffering carries the potential to bring people together and to form community.

[220] Young (2002) writes,

> What develops is a theology of presence in communion and community, a kind of contemplative mode of waiting on God with one another, which is far removed from political activism or patronising charity. There is mutuality in which grace is imparted to each, and each gives and receives (p. 1).

I wish to elaborate briefly upon the theological notion of presence. There is an emphasis in contemporary orthodox theology on the notions of "presence" and identification. Barth (1960) elaborates on the choice of God, where God makes a space in God's own being for humanity and does not choose to be God without humanity,

> It is when we look at Jesus Christ that we know decisively that God's deity does not exclude, but includes His *humanity*... In Him [Jesus Christ] the fact is once for all established that God does not exist without man (pp. 49-50)

Rahner describes the self-communication of God, where God's giving of Godself in love, God's communicating of Godself to the world, lies at the heart of the Christian doctrine of God. Moltmann has developed a theology of hope and of the suffering of God, where God gives up Godself for the sake of the other and is willingly present with the hopeless even at immense cost to Godself. For example, Moltmann (1974) quotes in *The crucified God* from a story recounted by Elie Wiesel in the concentration camps. Where was God during the hanging of a young boy? Wiesel's response was that God was on the gallows. God in love does not abandon humankind to its suffering. God is present, entering into the full depths of evil for the sake of solidarity with God's creation and overcoming evil on the third day. Finally, John Macquarie has advanced the concept of a dipolar theism, premised on the dynamic nature of humankind's capacity for self-transcendence and openness to God, and the eternal dynamic nature of God's capacity to accommodate Godself to humankind and to reach out to all people.

In a theology of presence, the cross is understood as the focus of God's presence with humankind, rather than as the price paid for the salvation of world. It is construed in terms of identification rather than payment. God is God Emmanuel. There is nothing that lies beyond the love and presence of God including torture. Therefore whatever one says about God, one is never able to say that any person has been *abandoned* by God. John Milbank has criticised this understanding on the grounds that it leads to a tragic (an exemplarist) soteriology, where all that one can say is that God is *with* humankind in its pain. That being said, it is *God* who is *with* humanity, and not merely another human person.

Hope in Faith and Light does not lie in removal of the disability. Rather Faith and Light maintains that new life is revealed, discovered and created through the celebration of difference. A fundamental tenet of the movement is that God reveals Godself in weakness. Through a radical acceptance of weakness, vulnerability and death, people discover the presence of the Trinitarian God in one another. A profound mutual respect for the otherness of the other accords dignity to each person. Faith and Light does not seek so much to create the perfect society as to welcome the fruits of the Spirit in the lives of each person.

Young (2002) argues that it was when Job was in the presence of God, that his questions no longer seemed to matter as much. Job was confronted by the miracle and the mystery of all creation, and found himself deeply humbled by all of reality (Job 42.1-6).[221] In a similar way, Faith and Light holds itself out as helping parents to *discover* God's presence in their pain, rather than as seeking to *explain* God's presence to them in the midst of their suffering. Therefore, Faith and Light could respond to parents' experience by making more specific the notion of presence as its understanding of a Christian response to suffering. As well as continuing to embody presence to parents through relationships of mutuality and reciprocity, it could promote ways of accessing and deepening their experience of God's presence in living perpetual parenthood.

Recovery of the contemplative dimension.

One of Faith and Light's charisms is the manner in which it holds together the active and contemplative aspects of Christian discipleship. Prayer is one of the three organising activities of the movement, along with sharing and celebration or fiesta. The Charter specifies that Faith and Light is "a community of prayer" (I.3).[222] The Guidelines offer suggestions for prayer each month. In the 2001-2002 Guidelines Father Joseph Larsen describes Faith and Light as "the special school of prayer." He suggests a form of prayer

[221] These remarks were made in an address to national chaplains at the Faith and Light International General Meeting in Rome on September 25, 2002.

[222] "... the personal meeting and the celebration find their culmination in prayer, in union with God and in the celebration of the Eucharist and/or other religious celebrations" (I.3).

particularly suited to the way of life of Faith and Light, which he terms the prayer of poverty or prayer of the poor.[223] He describes it as a "heart-to-heart" prayer, a prayer of presence and self-offering to the person of Jesus in trust, through the language of the body.[224] Father Larsen suggests that members make the prayer of the poor a daily ritual. In this way, Faith and Light as a movement invites its members to recover a contemplative dimension in their daily lives. It is a domain that participants did not mention specifically in their reflections on the role of Faith and Light in their family life. Contemplative practice might be a resource to assist parents in the enduring nature of their vocation and in responding to the specific issues they raised in relation to perpetual parenthood.

An attitude of abandon.

Father Larsen identified two touchstones in Faith and Light's way of life. The first was recognition of the suffering implicit in the human life and the choice to live the suffering in abandonment to God; the second was the gift of friendship as Faith and Light's principal response to suffering. Members in the focus groups spoke openly of the challenges they faced as "perpetual parents": fears around abuse of offspring or losing their offspring; the reaction of other people to their offspring; the need to advocate for

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[223] Father Larsen cites Ps. 131 as exemplifying the requisite attitudinal disposition. The translation he offers is:

Yahweh, my heart is not haughty
I do not set my sights too high.
I have taken no part in great affairs,
In wonders beyond my scope.
No, I hold myself in quiet and silence,
Like a little child in its mother's arms,
Like a little child, so I keep myself.
Let Israel hope in Yahweh
Henceforth and for ever.

[224] It is a prayer of the "body," where one is able to express oneself by one's body, even if one cannot use words. It takes the form of adopting a relaxed and unchanging position in silence with a straight back and open hands, breathing gently and regularly, and repeating "a single word, a word of love." Members may be gathered on chairs in a semi-circle around a prayer corner, while meditative music is playing in the background. It may last ten minutes. See Fr. Larsen's articles "A few words on prayer during our monthly meetings" in the Annual Guidelines 2001-2002 entitled *In the steps of the first Christian communities* (pp. 8-9) and "The prayer of the poor" in the Annual Guidelines 2002-2003 entitled *A journey together through the Gospel of John* (p. 68, Appendix 1). Both Annual Guidelines were published by Faith and Light International 3, rue du Laos, 75 015 Paris.

their offspring; the demands in transition periods; the problems with other caregivers. They articulated some of their suffering and the sources of pain. It seemed that the participants acknowledged readily the benefit of friendship through Faith and Light in their lives, as they spoke of the mutual support and understanding, the welcome and the interaction they experienced in the community.

Participants did not use any language suggesting trust in, and abandonment to God as a response to what they were living. Tina and Paul probably came closest when they reiterated the need to learn to "trust" when their son left the family home and was cared for by others.

> *Tina* No… it's hard for us to trust whoever, but we have been learned [*sic*] to trust…
> *Paul* You have to… *you have to* (italics mine)… not by choice… (1.35.1-4).

It seems significant that none of the participants raised the concept of trust in, or abandonment to God in relation to the challenges they endured in living perpetual parenthood. As mentioned above, there may be any number of factors contributing to the silence: the moderator's failure to inquire directly; deficient Christian teaching in the local community; a disconnect between the concept and the lived reality of parents. Nonetheless, given the central place afforded to the notion by the International Chaplain, Faith and Light is well positioned to instruct parents sensitively and respectfully in how to live perpetual parenthood with a disposition of trust in, and abandonment to, God.

Meaning-making and re-writing family narratives.

Reiss (1981) argues that families as a unit construct their own belief systems and paradigms through which they interpret themselves, others, intellectual disability, society and God. Rolland (1994) has written extensively on the influence of a family's belief system on its coping strategies in general, and its ability to adapt to the presence of intellectual disability in the family in particular. A family's belief system will have a significant bearing on how parents respond to the phenomenon of perpetual parenthood. Parents' difficulties in coming to terms with the enduring nature of their vocation might

signal the need for a re-evaluation of aspects of their belief system. It might entail reinterpreting aspects of their worldview and rewriting some of the family narratives. It would seem that Faith and Light has a particular role to play in this domain. The Charter identifies the recognition and calling forth of the gifts and of the beauty of people with an intellectual disability as an aspect of Faith and Light's vocation.[225] It states the need to see them "in the light of the Gospel," as well as to "understand their human needs in their suffering, and to know how to respond" (II.3). Participants in the focus groups referred to the way in which Faith and Light revealed the gifts and the beauty of their offspring, and allowed them to use their talents. In Wendy's words, "... and I think Faith and Light helps us to see the beauty of each one of these people who have developmental handicaps" (1.51.32-51.1). Julie remarked that "... These people [with an intellectual disability] can express themselves in other ways even if they can't do it like us..." (1.53.22-23).

Nonetheless the vocation of Faith and Light extends beyond calling forth the gifts and beauty of people with an intellectual disability. It contrasts a world of "competition, money and material pleasures" with a world of "tenderness and fidelity, of listening and faith" (I, Introduction). The movement invites a transformation of parents' perspective, not only in how parents see their offspring with an intellectual disability, but in the reshaping of a family's worldview and a rewriting of family scripts.

David Ford believes that L'Arche and Faith and Light has a particular contribution to make to the *wisdom tradition* in Christian heritage.[226] He observes that it finds expression

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[225] "Faith and Light gives to persons with an intellectual disability the possibility of recognizing and using their gifts and discovering the joy of friendship" (I, introduction). People with an intellectual disability are "not imprisoned by convention" and can therefore celebrate more freely. They live more simply in the present moment and possess "humility and transparency" (I.2). They have "simplicity of heart" and "can become a source of unity" (I.5). They enjoy a capacity for welcome and for love, and are "prophetic in the area of the heart and of tenderness, and in what is essential in the human person" (II.2).

[226] He offers a credal statement on the heart of L'Arche in his paper *What is the wisdom of L'Arche?* delivered at L'Arche Trosly, Trosly-Breuil, France on December 15, 2002.

> God,
> through the wisdom of the Gospel,
> meets the brokenness, anguish,
> and deepest desires of human bodies and hearts
> in a long-term community

more in people's lives and relationships, in apprenticeships, practices and community structure than it does in specific teachings or writings. Dimensions of the wisdom[227] of L'Arche and Faith and Light that he identifies include: the prophetic, with implications for Church and society; the learning-related, where apprenticeships are *to* those with an intellectual disability; the institutional, in Faith and Light's ability to maintain a core identity while adapting to local culture; the fragile, with the potential for error; the Scriptural, in the hermeneutical insights it generates; and the Gospel-oriented, through its affirmation, critique and transformation of the created order. Ford (2002, November) highlights the way in which the wisdom of L'Arche and Faith and Light challenges the constructs of one's worldview. It raises questions around one's priorities in life, one's understanding of human worth and dignity, of suffering and death, and of power and weakness.[228] Therefore, part of the implicit role of Faith and Light in the lives of families is to incarnate the Gospel in a way that affirms the goodness of the created order (incarnation), that offers a critique of a secular worldview (crucifixion), and that lives a foretaste of God's new creation of transformed relationship (resurrection) (Ford, 2002a, December, p. 7). It offers a transformed way of understanding Scripture and of living the Gospel.

While it was not raised by the participants, one of Faith and Light's potential roles in responding to the phenomenon of perpetual parenthood is promoting the transformation of restricting family paradigms and facilitating the rewriting of family narratives. Faith and Light is a Christian community grounded in Scripture and Tradition that invites third

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of mutual presence,
service,
and friendship.
This is a sign of hope for all people.

[227] Ford (2002a, December) defines wisdom as "a matured perception, understanding and judgement closely related to living well before God. It unites heart, mind, imagination and will in relation to the purposes of God in actual life" (p.1).

[228] "L'Arche calls into question the nature and role in our lives of health, wealth, education, status, success. It raises questions such as: How do we understand the human worth, dignity and fulfilment of ourselves and others? How do we cope with vulnerability, suffering, or death? How are power and weakness related? Whom do we value most, and why? What happens to our hearts and souls when we are opened up to friendships such as those in L'Arche? What might happen to churches, to other religions, to secular groups, or to social services if they were to learn and practice some of the wisdom being learned at L'Arche?" (Ford, 2002, November, p. 12)

order change in the family life of its members in social scientific terminology. It provides the means by which parents are able to reinterpret the perpetual nature of their vocation.

I conclude this section with a reflection on the mystery that lies at the heart of the families represented. While conducting research with the participants, I was struck by the need for humility and profound respect as I approached the essential *mystery* of how parents create family with their offspring with an intellectual disability. In Father Larsen's words, Faith and Light offers an encounter with *mystery*, which leads people to be able to say "Abba Father..." (J. Larsen, personal communication, September 27, 2002). [229] Faith and Light recognizes the fundamental mystery of God and of the other. Part of the role of Faith and Light is to permit and to encourage parents to reflect theologically on their experience. In Gerkin's schema this reflection on experience leads to transformed experience. Faith and Light through its chaplains has a role in guiding parents in their reflections, including their experience of perpetual parenthood. It will entail listening to stories.[230] One of the roles of the chaplain in Faith and Light is to enter into dialogue with parents in such a way, that they are able to listen to their own stories and locate them within the Christian story. In this way Truth can make its way in them and inner freedom can emerge (Fr. Rami, personal communication, September 27, 2002).

Summary

I have examined how the phenomenon of perpetual parenthood and Faith and Light might inform each other by asking two questions: How *does* Faith and Light respond to parents' experience, and how *could* Faith and Light respond to their enduring vocation as parents? In summary, the data seemed to demonstrate that those aspects of Faith and Light that parents identified as helpful for themselves (mutual support and understanding, welcome, interaction and friendship) and for their offspring (recognition and use of gifts, personal

[229] In a similar vein, Frances Young (1997) describes the shift amongst a group of theologians gathered to reflect on the nature and role of the L'Arche community from a paradigm of *problem-solving* to one of *mystery-encountering* (p. x).

[230] Frances Young (personal communication, September 25, 2002) believes that one of Faith and Light's contributions to theology is the importance of story, parable and symbol in constructing theology. Symbols are the building blocks of theological language. In a similar way, mime, images and tangible objects play a vital role in Faith and Light meetings.

growth, friendship, listening and acceptance, Christian formation) were all charisms that appeared in the movement's foundational documents (the Charter and the Constitution), or in the thought or writings of recognised authorities in Faith and Light. Each of the aspects that parents identified appeared in the examined sources. Parents suggested some changes to the format of meetings to promote the active participation of their offspring. They also found it helpful to meet together as parents to listen to each other's experiences and to share information.

Conversely, there were characteristics of Faith and Light named in the above sources that might assist parents in living their perpetual vocation. Faith and Light appears to have a role to play in the spiritual-vocational dimension of the lives of parents and their families. It embodies presence as a response to one's own suffering and the suffering of others, and promotes its potential in bringing people together. It seeks to facilitate parents' experience of God's presence in living perpetual parenthood. It aims to assist parents to recover the contemplative dimension in their Christian life as a resource in responding to the issues they identified. Faith and Light has the resources to guide parents in cultivating an attitude of abandonment to, and trust in God, in learning to live with the enduring nature of their vocation. Finally, Faith and Light is a community that embodies Christian wisdom and practice. Through an explicitly Christian understanding of intellectual disability, the human person, relationships, community and God it holds out to parents the potential for third-order change, a reinterpretation of worldview and a rewriting of family narratives.

Perpetual Parenthood and Theological Pastoral Care and Counselling

I address the second question outlined at the beginning of this chapter, How do perpetual parenthood and theological pastoral care and counselling inform each other? What are the implications of the phenomenon of perpetual parenthood for theological pastoral care and counselling, and how might a theological pastoral care and counselling respond to the phenomenon of perpetual parenthood? Some of the implications will have been raised in the previous section. I expand upon those that I have not previously discussed.

How Does Perpetual Parenthood Inform a Theological Pastoral Care and Counselling?

In the previous chapter I suggested that the organising concept arising out of the focus group data was the phenomenon of perpetual parenthood, implicit to which was the ambivalence or the dilemma of holding on and letting go. I argued that there were four themes consistent with the organising concept of perpetual parenthood: the challenges parents face, particularly around the threat of abuse and the need to advocate for their offspring; their concerns over the adequacy of care their offspring receive from caregivers and health care professionals; parents' investment in their offspring and their particular knowledge of them; and the impact of the various transitions or segues across the life cycle on the family, parents and offspring alike. Each of these issues bore a correlative relationship with perpetual parenthood.

A nuanced understanding of parents' experience.

The first implication of perpetual parenthood for theological pastoral care and counselling is that it offers a more nuanced understanding of the lived reality of parents of offspring with an intellectual disability. It identifies particular issues parents may be dealing with, and some of the struggles they face. In this way, pastoral carers, in having a clearer understanding of parents' experience, may be better placed to respond to their needs.

The contextual nature of family life cycle theory.

Second, the phenomenon of perpetual parenthood highlights the contextual nature of the experiences of parents of offspring with an intellectual disability. Their individual and family life cycle stages may differ from those of parents of conventional families. For example, most family life cycle models propose a launching phase, when children leave the family nest. Some of the tasks commensurate with this stage in Carter and McGoldrick's (1999a) model, include renegotiation of the marital system as a dyad, the development of adult-to-adult relationships between grown children and their parents,

and realignment of relationships to include in-laws and grandchildren (p. 2). It is self-evident that in families with a member with an intellectual disability these tasks may not be applicable. There may not be a launching of an offspring with an intellectual disability; parents may experience difficulty in developing an adult-to-adult relationship with their offspring, who may remain dependent on their parents; offspring with an intellectual disability may not find life partners, nor have children of their own. Hence, family life cycle models, as with other systemic developmental models predicated upon family members without a disability may be of limited relevance in framing pastoral care to parents of offspring with an intellectual disability. The phenomenon of perpetual parenthood invites providers of pastoral care and counselling to be more open and respectful of the various configurations that parents have worked out, or have found themselves needing to adjust to, in providing care for their offspring with an intellectual disability.

How Might a Theological Pastoral Care and Counselling Respond to Perpetual Parenthood?

Having asked how perpetual parenthood could inform a theological pastoral care and counselling, I now turn the question around to inquire how this approach to pastoral care might speak to those issues parents have raised in their enduring vocation as parents. I refer the reader to the previous section for additional contributions that a theological pastoral care and counselling might make to the phenomenon of perpetual parenthood. In responding to the phenomenon of perpetual parenthood, theological pastoral care and counselling will promote ecclesial teachings and practice that Faith and Light embodies in its corporate life: *presence* as a response to suffering; recovery of the contemplative dimension; a stance of abandon to, and trust in, God; and use of the Christian metanarrative to transform restricting family paradigms.

The holding on and letting go ambivalence.

A further response of a theological pastoral care and counselling will be the location of the parental ambivalence over holding on and letting go in the nature and activity of God. The holding on/letting go dilemma is one that resonates with the being of God. Frances Young, mother of Arthur who has an intellectual disability, Methodist minister and theologian argues that God's act of creation is an act of abandonment.[231] God abandons or lets go of creation so that creation has the freedom to be fecund and prodigious, and to mutate. Freedom and the growth to maturity entail significant risk.[232] In the act of creation, God withdraws, abandons and holds creation at a distance. In some ways it parallels parents' letting go of their children.[233] Paradoxically, in the incarnation there is the story of Jesus entering fully into the heart of the suffering and darkness that inhabits all of the created order; God draws creation intimately to Godself. In a sense it resonates with parents' commitment to their offspring. Orthodox Christian theology seeks to hold both these Truths together. In so doing, God's presence is both discovered and revealed in the most unlikely places, the most unlikely of all being the cross. Therefore, the life, death and resurrection of Jesus Christ can be said to speak to the existential ambivalence of holding on and letting go. The cross may be seen as God's provisional and final resolution to the fundamental human ambivalence of holding on and letting go.

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[231] Frances Young (personal communication, September 25, 2002) cites Simone Weil, who has written, "The act of creation was an act of abandonment." The following footnotes expanding on Young's theology of limit come from the same source.

[232] In the same address to chaplains delivered at the Faith and Light International General Meeting in Rome 2002 noted above, Young used the metaphor of a butterfly. One cannot hold on to a butterfly without damaging it. One can provide a space with one's hands within which the butterfly can fly. In a similar way God holds creation in such a way that it can live and move and have its being without being crushed or damaged.

[233] Her argument runs in this way. If God is infinite, nothing other than God can exist unless God withdraws Godself to make space for what is other than God. (She uses a space metaphor even as she acknowledges that it does not provide an adequate fit for the boundlessness of God). Therefore Creation could only occur where God made space for what is other than God to exist with all the concomitant risks of accident and disobedience. The paradox is that sometimes through the accidents in creation that are inherent in the risk of abandonment, new and good things come about. There may be a sense in which humankind prevents too many accidents. There is an immense amount of life created that does not come to life or maturity.

Ad hoc use of social science theories and interventions.

In describing a theological pastoral care and counselling in Chapter Two, I proposed an asymmetrical relationship between orthodox Christian theology and related secular disciplines in understanding and defining those categories relevant to the field of pastoral care. This does not mean dismissing or even downplaying contributions from the social sciences. Rather, one has recourse to insights from natural fields of inquiry on an ad hoc basis, where they assist with explicating or interpreting the experience in question. Such insights however never supplant the Church's own categories for the understanding and delivery of pastoral care and counselling. Thus, a second contribution of a theological pastoral care and counselling to the phenomenon of perpetual parenthood is the utilisation of those social science theories and interventions that assist with a more nuanced understanding of particular issues that parents and families of offspring with an intellectual disability might have faced, are facing or will face. These theories might explicate intrapsychic or interpersonal dynamics operative at a biophysical, psychosocial or spiritual-vocational level in family life that contribute to parents' reported issues. In the previous chapter, I have given some examples of systemic and developmental theories that might shed some light on parents' experiences, and thereby assist with tailoring pastoral care and counselling to their particular needs. Those theories and related interventions included: Bowlby's attachment theory, Boszormenyi-Nagy's concept of relational ethics and asymmetrical parent-child relations, Ricoeur's narrative theory and re-storying, grief theory and the concept of relocation, a pastoral theological perspective on leaving home, and the use of ritual.

Ecclesial practices.

In Chapter Two, I argued that pastoral care is sourced in the life, death and resurrection of Jesus Christ and all that those dimensions say about the divine reality. It is a ministry of the Church, and more concretely of the local and visible faith community, the primary context in which Scripture and Tradition function. It is formed and informed not only by Holy Scripture, but by the sacramental life of the Church. Hence, there are ecclesial

practices that may assist parents in living the implications of perpetual parenthood The provider of pastoral care and counselling operates as a representative of a faith community. Implicit in what is being offered parents are the resources of the Church, including those of the particular faith community of which the carer forms a part. Ideally, the carer holds out membership of a welcoming and caring community, where parents can discover a sense of belonging. The faith community is organized for and grounded in worship, prayer, the preaching of the gospel, the study of scripture, the faithful reception of the sacraments and service to those in need. These are all resources of which parents may avail themselves in responding to particular issues associated with perpetual parenthood.

Faith and Light and a Theological Pastoral Care and Counselling

The third and final question I posed at the outset of this chapter was, How do Faith and Light and a theological pastoral care and counselling inform each other? I explore the question from both angles, considering what Faith and Light might model in its understanding and delivery of pastoral care, and what a theological pastoral care and counselling might have to offer Faith and Light.

How Does Faith and Light Inform a Theological Pastoral Care and Counselling?

Parents identified what they valued in Faith and Light meetings. They experienced support and understanding, welcome, interaction and friendships. They perceived that the community called forth the beauty and the giftedness of their offspring, facilitated their growth and provided friendship, offered them Christian formation, and listened to and accepted them. In short, parents reported that they felt cared for, and that their offspring were being cared for. It could be said that Faith and Light extends pastoral care and counselling to these families in a manner that was helpful and appreciated. Faith and Light operates as an extension of the Church, and makes use of ecclesial practices in its corporate life. It is a community that gathers each month to listen to Scripture, to enact it and to reflect upon it. It offers worship to God during these meetings through informal

liturgies, where individual members are given opportunity to pray. Faith and Light promotes relationships of mutuality and reciprocity through friendship issuing from the Scripture and Tradition that forms and informs the community. It encourages unity through attentive presence to one another in response to the suffering of people. Faith and Light models how pastoral care and counselling can operate, when it is ecclesially located and theologically informed. It affirms the congregational context of pastoral care, the delivery of care through informal relationships and the role of liturgy in expressing God's care for people (Gerkin, 1997, pp. 92-94). It reasserts the importance of listening and a stance of openness, warmth, empathy, understanding and acceptance in the pastoral care relationship. It suggests that pastoral care and Christian education or catechesis are not necessarily separate domains. Indeed, the provision of pastoral care might include catechumenal elements. It encourages attention to the relationship of friendship as a possible resource in the interpretation and delivery of pastoral care and counselling.

In summary, Faith and Light not only affirms the workability of a theological pastoral care and counselling; it provides an embodied model of what it might look like in practice, thereby defining some of the model's salient features.

What Might a Theological Pastoral Care and Counselling Have to Offer Faith and Light?

A theological pastoral care and counselling would bring the full ambit of the Church's theological resources to bear upon Faith and Light. I have argued that practical theology, that branch of theology traditionally held to underwrite pastoral care and counselling, is first and foremost *theology,* and is entirely derivative of its biblical, systemic/dogmatic and historical forebears. Hence, it is orthodox Christian theology that provides the intellectual context within which pastoral care and counselling is construed. A theological pastoral care and counselling provides a theological framework against which and within which, the theology, spirituality and ethos of Faith and Light can be located and critiqued. It will throw into starker relief those theological doctrinal loci that are being privileged in Faith and Light's theological understanding of its identity and mission. I

conclude this chapter with a preliminary and cursory theological critique of Faith and Light.

Some Theological Questions for Faith and Light

In the second chapter I advanced the notion of a *theological* pastoral care and counselling that emphasised its ecclesial location and the asymmetrical nature of the relationship between theology and experience, and theology and the social sciences. In this section, I return to the thrust of the argument of the second chapter, in engaging in a theological reflection on Faith and Light. I underscore the *theological* nature of the reflection, which locates some of the theological doctrinal loci of Faith and Light as identified in its foundational literature within the spread of orthodox Christian theology, and which offers a critique of them.

The foundational literature outlined in the third chapter includes the Charter and the Constitution of Faith and Light, and the writings of Jean Vanier, one of the co-founders, and Father Joseph Larsen, the International Chaplain. The thought and vision of Vanier has been highly significant in the inception and evolution of the community, including its foundational documents. It may be instructive to explore the ways in which Vanier develops his theological framework, before turning to examine some of the key ideas comprised therein. I propose to explore what Vanier is privileging when he spells out what lies at the heart of the theology and spirituality of Faith and Light. He evokes certain Christian doctrinal loci. What remains ambiguous is the relationship in which the Faith and Light categories stand to Christian doctrinal loci as traditionally conceived.

Beginning Theology with Experience

In reflections on the theology and spirituality of L'Arche/Faith and Light, the *experience* of those communities is the beginning point. Their experience is central to their expressed understandings of categories such as God, Jesus Christ, salvation, the human person,

community life and relational dynamics, and suffering and joy.[234] There is a correlative move made between the experience of L'Arche/Faith and Light, and God. There is a risk that in beginning with the experience of Faith and Light that the experience will determine the parameters and furnish all the categories for the correlative exercise. Those theological categories that lie outside the ambit of the community's experience may be omitted from its theological reflections. The experience of Faith and Light may highlight certain Scriptural texts, as identified in Chapter Three. What happens to other Scriptural texts not highlighted by experience? Will Scripture only speak when the experience of Faith and Light provides a conceptual and contextual matrix? Axiomatic to Vanier's thought appears to be the proposition that God reveals Godself pre-eminently amongst the poor. It invites the question, Does God reveal Godself primarily through the poor as opposed to through other means, such as Scripture, or the sacraments? If one appropriates the Gospel in this way, does it lead to a truncated vision of other theological doctrinal loci? [235]

It is important to consider how the other theological dominoes might fall as a result of this beginning. How can one be sure in a theology of Faith and Light that one has not left behind the realm of divine activity? Vanier privileges the experiential, to talk of the divine in human terms. What would happen if one embarked from a different place? What if one began from a Christological or a pneumatological register, for example? What would one then say about the nature of community, the character of the human heart, and the role of suffering? Before embarking on this cursory survey, I need to acknowledge that Vanier himself might respond that his intent was never to construct a systematic theology. He might say that he is simply reflecting on aspects of God's being and activity, and aspects of Christian life arising out of his experience of seeking to live

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[234]For example, David Ford (2002a, December) identifies two types of register in which God is revealed in the experience of L'Arche: first, "in brokenness, weakness, disability, pain, vulnerability, risk and death"; and second, "in new forms of beauty, service, community, learning and friendship." Perhaps these could be broadly described as a register of suffering and a register of joy.

[235] It leads to further questions. Do the vulnerable mediate grace by virtue of their vulnerability? What is it in the vulnerable or the broken that needs to be redeemed? I advance these questions tentatively, wary of using theological argument to detract from an inspirational devotion to the well-being of those who are marginalised. One might well accept the teaching of the Roman Catholic Magisterium in concert with the Gospels, concerning the "preferential option for the poor," without identifying the "poor" as the primary locus of revelation.

the Gospel in community with people with an intellectual disability. Indeed the questions I raise border on the inconsequential when set against his exemplary apostolic witness to the ministry and mission of Jesus Christ.

Hermeneutic of Brokenness

Any reflection on the experience of Faith and Light must reckon with the reality of intellectual disability. It is cast as a form of brokenness. Part of the pain of Faith and Light may be that it is predicated upon and built around a brokenness that cannot be made whole as one would traditionally conceive wholeness. A person with an intellectual disability is not going to become a person without an intellectual disability. Given the choice between having a disability and not having a disability, the person seeking wholeness would probably choose the latter. The intractable nature of this form of brokenness will need to be addressed in any theology arising out of the experience of Faith and Light.

It may be that an *hermeneutic of brokenness* is a response to this question. That is to say, *brokenness* is adopted as a lens through which Scripture and Tradition is interpreted and understood. It becomes a contemporary hermeneutic, which reinterprets traditional doctrinal loci. While such practice may yield fresh insights into the Gospel, it is important to subject *any* hermeneutic adopted to scrutiny. Part of the inquiry would include identifying and articulating the hermeneutic being employed, and advancing substantive grounds for the choice of this particular hermeneutic over another. According a privileged position to any hermeneutic, particularly where its use may not be explicitly acknowledged, risks distorting Christian doctrine as traditionally conceived. A hermeneutic of brokenness will edit the reading of Scripture and therefore the construal of certain Christian doctrinal loci.[236] For example, in an unpublished paper entitled *The contribution of L'Arche to theology* Frances Young (2002, December) appears to adopt

[236] David Ford (2002a, December) argues that the L'Arche/Faith and Light community takes the "straightforward" or "plain" or "literal" sense of scripture very seriously, and goes beyond it to make "all sorts of thoughtful improvisations, new connections, and applications." I wonder whether the hermeneutic of "brokenness" can be said to allow for a plain or literal reading of Scripture.

an hermeneutic of brokenness, and is therefore constrained to read brokenness into her doctrine of creation and into her eschatology. The hermeneutic appears to privilege the humanity of Jesus Christ in her Christology at the cost of his divinty. It couches soteriology in terms of radical solidarity with the marginalised, and ecclesiology is centred on those most broken. It emphasises the horizontal dimension in her doctrine of sin, where the Fall is cast in terms of the building up of barriers to conceal vulnerability and promote the illusion of self-sufficiency.[237] One wonders whether the doctrine of grace is also edited through this hermeneutic? Whose work is the taking down of the barriers of fear built around the human heart? Is one expected to dismantle one's own barriers? Is it the experience of transformative community centred on the most broken? The fundamental question remains, On what grounds does Young base her choice of this hermeneutic? Why is brokenness per se revelatory of God? Is there Scriptural warrant for it? The passage from First Corinthians (1 Cor. 1.18-31) that is often cited to support brokenness as a privileged revelatory locus appears to be a Christological assertion rather than a metaphysical one.

The Gospel is eruptive, disruptive, and arresting of the world. It brings one face to face with God in the humanity of Jesus. It is grit in the machinery of any attempt to create an explanatory schema. The Gospel judges and forgives the reader. Its hermeneutic arises out of stories read as they are. It is not a hermeneutic based on privileging some stories and diminishing others, where the reader edits her or his story to fit the meaning. The reader makes a decision on how to read the text based on the identity of Jesus Christ. Hans Frei (1993a) talks of the "unsubstitutionality" of the text: either Jesus Christ is who he says he is, or one is forced to dismiss the entirety. It might be that adopting a hermeneutic of brokenness mitigates against a "plain reading" (in Frei's terms) of the text.

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[237] By way of contrast, the myth of Genesis seems to set up sin as the human doubting of God, and the blaming of one another for the manifestation of the rejection of God. A traditional doctrine of sin as extrapolated from the Genesis account begins with the breakdown of the vertical dimension of communion with God.

The Vulnerability of God

The related concept of the vulnerability of God as revealed in Jesus Christ appears frequently in Vanier's works. While as MacKinnon (1987) maintains that God is "archetypically and immutably self-limitation, and is therefore love," it is not the same thing to speak about the vulnerability and brokenness of God and the vulnerability and brokenness of humanity (p. 235). Can one say that the cross of Christ renders the brokenness of the human body as the privileged locus of divine revelation? God chose God's own vulnerability to reveal Godself. Whether *any* vulnerability per se can reveal God is another question. It seems that there is a radical difference between God's vulnerability and humankind's vulnerability. God's vulnerability in Jesus Christ was freely chosen. Jesus is not poor under any external constraints. How many people could say in honesty that their vulnerability in whatever form it manifests itself is freely chosen? It is the juxtaposition of God and God's vulnerability which is revelatory.[238] The uniqueness of the cross is essential. Where does one learn that the Gospel is good news? Is it wherever one sees pain or brokenness? The Gospel is good news in and of itself in the particularity of the cross, where God in Jesus Christ through the Spirit effects reconciliation between God and humankind. Reconciliation includes Jesus' shedding of blood, the propitiation and the atonement. It is one thing to say that the cross of Christ makes sense in a community founded on brokenness and pain. It is another thing to say that one's own brokenness makes sense in that community, or that the community makes sense of one's own pain.

Consider the irony of the Pharisees' response to Jesus' raising Lazarus from the dead. Rather than being awestruck by Jesus' power, they plan immediately to kill him. There is nothing in the Gospels that would indicate that Jesus thought of himself as invulnerable

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[238] One of earliest texts to announce this theme in the 20th century was *Immutable mutability of God,* which addressed the logical incompatibility of two substances in God: the unchangeable and the changeable. These two substances can only meet tangentially. Barth and Moltmann maintain that because in Christian revelation God is found at the most intent point of change, that is at the point of death, God's greatness lies not in God's remoteness from change, but rather in God's capacity to be God in the midst of the most profound change. It leads to a redefinition of transcendence which holds together power and weakness, eternity and temporality. Barth has argued that the glory of God is God's capacity to be humble, to be a baby at the breast of Mary and still to be God.

even though he brought a dead person back to life. It demonstrates his absolute vulnerability. Whatever power Jesus had, it is not immune from the threat of weakness. Yet it is obvious that Jesus' power is no trivial power. Jesus had divine power to give life in death. (See Rom. 4.17. "... in the presence of the God... who gives life to the dead and calls into existence the things that do not exist").

Perhaps what may be required is a more sophisticated or nuanced reading of God's vulnerability. William Temple's criticism of Charles Gore in the 19th century posed the question, "Who was being immutable when God was so mutable?" It may necessitate the paradoxical assertion that God is at once both invulnerable and vulnerable. God is the vulnerability of invulnerability, and the invulnerability of vulnerability as the Anglican theologian Donald MacKinnon has observed.[239] It is the paradox of the man Jesus being both fully human and fully divine, the "haunting alternation" between the familiar and the

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[239] It is in the person of Jesus Christ that the juxtaposition of God's invulnerability and vulnerability finds its essential expression. It is a paradox that is axiomatic to an understanding of the Triune God. MacKinnon (1987) teases out some of the implications of the paradox in the following quotations from *Themes in theology: The threefold cord: Essays in philosophy, politics and theology.*

> If, however, we allow the mystery of the Incarnation to shed its light upon the formal order of relations of creature to creator, and creator to creature, and if we give to that mystery the authority it claims, we must reverse any understanding of divine transcendence that sees transcendence as only safeguarded by refusal to admit any sort of self-limitation into the divine, any sort of self-committal in creation that would allow a genuine, if asymmetrical, reciprocity in relations of creation and creator. Of course God must (and the *must* is of logical necessity) remain invulnerable. One might say that his aseity can be mythologized in terms of an ultimate invulnerability (pp. 183-184)

MacKinnon emphasises that the act of the Incarnation lays bare "the continual interpenetration of dramatic and ontological" (p. 234), before maintaining that the divine vulnerability reaches its climax in the cross and its historical *sequelae*. It is here that God is "decisively revealed as putting himself at the mercy of the world" (p. 234). He continues his argument.

> In the complex development of Trinitarian theology, one constant thread is surely the need so to conceive God as He is in Himself that this acceptance of vulnerability is judged as congruous with, indeed expressive of His being as He is in Himself. It is indeed totally innovative: yet where it reaches its point of concretion in the ministry of Jesus it bodes forth the reality of God's self-definition as Triune. The temptation of Jesus in the desert conveys the very presence in Him of this three-foldness of the divine being. For he sets Himself over against the Father in the power of the Spirit in as much as in eternity He is self-giving response to an eternal affirmation. Because God is archetypically and immutably self-limitation, and therefore love, He is able to assume into Himself not only the different limitations involved in creation, but the more sombre vulnerability involved in taking to Himself the substance of human history in Jesus of Nazareth. Yet the kenosis, whose depths we have not begun to plumb, is not strange or alien to His being, but the declaration of its substance and the disclosure of the inwardness and manner of His power... *The paradox of the vulnerability of the invulnerable, of the invulnerability of the vulnerable remains, and something of the historical failure of Christianity in practice and in theory, stems from deliberate retreat from facing its implications* [italics added] (1987, p. 235).

strange, the temporal and the eternal, the human and the divine.[240] Perhaps a fairer reflection of Christian Truth is given by recognising and acknowledging the aseity of God along with God's identity with humanity.

Christology

The Christological question is central to a theological understanding of Faith and Light. Based on his experience of community living with people with an intellectual disability, Vanier emphasises the "mystery of the poverty and the weakness of Jesus." He asserts that Jesus Christ *is* the poor.[241] The universalisation of a particular theory (such as theological anthropology) risks obscuring the particularity of the incarnation, crucifixion and resurrection of Jesus Christ. Can one say that Jesus *is* the poor? There is scriptural warrant (see Mt. 25. 31-46). Yet one would also need to acknowledge that Jesus himself proclaimed, "You always have the poor with you, but you do not always have me" (Jn. 12.8). Jesus may be the poor; Jesus is also Jesus. He is other than the poor. His particularity cannot be effaced by pointing to the poor. There is a risk that the particularity of Jesus of Nazareth is swallowed up in the category of the poor. To do so would simply render him as a cipher for categories of the human situation.

Christologically speaking, Scripture clearly witnesses to Jesus Christ having entered fully into human poverty and weakness, brokenness and woundedness. It is obvious that the experience of Faith and Light would correlate with this Christological dimension.

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[240] The term "haunting alternation" comes from MacKinnon (1987, p.179).

> For Christ comes before us, or at least it is possible that he is in fact so presented, as one who violates the contrast, or in old-fashioned evangelical language, bridges or straddles the gulf between human and divine: and this he does not by arrogance or assertive claim, but by a strange, *haunting alternation*, even interpenetration of humility and authority, receptivity and confident demand... One should not attempt to iron out the inconsistencies [of the narratives in the Gospels], but rather to see their presence as an invitation to more searching enquiry: finding in that presence evidence that the reality of Jesus defied any sort of easy, and indeed most sorts of comparatively painful, assimilation. This strangeness may be judged rooted in, and expressive of, the way in which he lived uniquely as the frontier of the familiar and the transcendent, the relative and the absolute, and by so standing, demands that our every conception of both alike be revised (pp. 179-180)

[241] "Jesus does not just serve the poor, he becomes one of them" (Vanier, 1995, p. 21). The question remains, "Where did Vanier learn that in experiencing the poor, he experiences Jesus?" What is the epistemological foundation which enables him to identify the poor with Jesus? Vanier would probably point to Scripture and the Tradition of the Church.

Whether the experience of Faith and Light would place the same emphasis within this category on Jesus having borne the sin of humankind remains another question. Yet this is not the only trajectory of the Gospel. The two natures Christology has arisen in the life of the Church, because the early Church Fathers perceived the need to give equal attention to the other trajectory. Jesus Christ was the one who was the manifestation of God's glory, and who had the power to give life, even life out of death. The claim of the New Testament tradition is that the subject of the life of Jesus of Nazareth is God.

The presentation of Jesus Christ in the Gospel accounts is of one who heals people and sets people free. His disciples are those who exercise this same ministry in the power of his name. In Acts 3, when Peter and John encounter a man with a congenital physical disability ("lame from birth"), they adjure him to "stand up and walk" (3.6), whereupon the man jumps up and begins to walk. He enters the temple "walking and leaping and praising God" (3.8). On a plain reading of the Gospel accounts, Jesus is not presented as one who is simply *present* to people in their brokenness.[242] He is the one who sets people free, even as he enters into the poverty, weakness and brokenness of others. Unless there is a predetermined hermeneutical matrix through which the Gospel is read, one will extract from the Gospel accounts the portrayal of Jesus as one who sets people free. To categorise Jesus as one who is merely present to people in their brokenness and vulnerability and who calls people to be together around their brokenness is a substantive editing of the text. Admittedly one could argue that healing and being set free finds its lived expression not so much in individual physiological transformation but in and through a particular form of community life radically committed to relationships of mutuality and reciprocity.

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[242] I have discussed the concept of *presence* as a response to suffering in Faith and Light earlier in the chapter. Frances Young (2002, December) describes it as a "contemplative waiting on God with one another" that invites a grace-imparting mutuality and fosters dignity for each person through mutual respect (p. 1). Given the place of suffering and pain in Faith and Light, and the response of presence, one wonders whether the Advent cry of lament can still find voice. "Cry aloud, O daughter Zion!" One wonders whether this lament needs to be given liturgical expression in the corporate worship of the community? Admittedly the question then arises, Is this cry of distress more an articulation of the anguish of those without an intellectual disability than those with one?

Soteriology

Vanier himself does not articulate a doctrine of creation, nor one of original sin. One wonders if there is not a doctrine of creation, whether there can be an adequate doctrine of new creation. There is a risk that soteriology is couched merely in terms of transformed and transforming community with the vulnerable. The question arises, Are there other expressions of salvation which may be available to Faith and Light? How else might healing, being set free, and the Reign of God be interpreted in the context of Faith and Light? One might also enquire whether Vanier attributes to community life with the vulnerable the power to transform the heart? Is there not something that needs to be pre-operative in the human heart to allow people to live together in community in this way?

A doctrine of salvation traditionally conceived encompasses more than transformed and transforming community. Faith and Light articulates and lives a particular set of the benefits of Christ's passion that find expression in community with those who are vulnerable and broken. There is a risk that the soteriology of Faith and Light is merely exemplarist, which may become a counsel of despair. Vanier reiterates that Jesus did not come to serve the poor; he came to be poor. Does the follower of Jesus continue in brokenness and woundedness in order to be like those who are broken and wounded? An exemplarist soteriology obscures the exchange that Jesus Christ wrought through his death and resurrection that lies at the heart of any coherent doctrine of the atonement. It is one thing to speak of the kenosis and therefore the poverty of Christ in his earthly life, but is he still poor as the risen one? Why then would St. Paul speak of the inestimable riches of God's grace towards us in Christ Jesus? "For you know the generous act of our Lord Jesus Christ, that though he was rich, yet for your sakes he became poor, so that by his poverty you might become rich" (2 Cor. 8.9). Pauline theology would argue that the poverty of Jesus engenders not poverty but richness and abundance in the disciple's life. Is there a risk of taking on work that Jesus' life, death and resurrection have already achieved on behalf of humanity? Does an exemplarist soteriology threaten the once and for all, then and there nature of Jesus Christ's work? Humanity is called to live its brokenness. It lives its brokenness as those in whom God has already begun a good work.

The crucifixion is inevitably and inexorably linked with the resurrection. That is the Gospel, the good news.

E. C. Hoskyn expresses the inseparability of Good Friday and Easter Sunday in Christian soteriology by referring to the "Death-Resurrection" of Jesus as the salvific event.

> Admittedly there is a tendency in Anglican soteriology to move too quickly from the Crucifixion to the Resurrection. There can be a triumphalism that underwrites Anglican Eucharistic worship. Anglicans often need to be reminded that the glory of Jesus Christ is in the cross, while acknowledging simultaneously that such glory in the cross arises out of the resurrection. Nonetheless, it is by the power of the *resurrection* that God's presence and activity is mediated through the Eucharist and the washing of feet. Similarly St. Paul's existential apprehension of the cross is balanced with the *renewed life* afforded by the Holy Spirit.[243] For St. Paul, this dialectic between death and life finds its ultimate resolution eschatologically (see 1 Cor. 15.19).[244] Therefore, an orthodox Christian theologian might argue for a soteriology in Faith and Light which is more thoroughly Christological without losing any of its anthropological purchase.

Vocation

It is self-evident that God calls and needs people to collaborate with God and others in the furtherance of God's reign in creation. Nonetheless, there are many different ways in which the collaboration finds expression beyond forming intentional community with those who are regarded as wounded or vulnerable. There are whole other tracts of human experience that represent a faithful response to the Gospel. A soteriology that is more explicitly Christological could lead to a broader understanding of Christian vocation that accommodates and affirms different conceptions of *imitatio Christi.* With the emphasis upon vulnerability and brokenness in the theology and spirituality of Faith and Light, one

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[243] See for example, "We are… always carrying in the body the death of Jesus, so that the life of Jesus may also be made visible in our bodies" (2 Cor 4. 8-10).

[244] Moltmann (1990) expresses the death/life dialectic in the person of Jesus Christ in the following way:

> This means we must even add that Jesus suffered death in "the power of indestructible life" (Heb. 7.16), and through this power of the "eternal Spirit" (9.14) in his death destroyed death. Consequently, through the slain Christ, indestructible life is opened up to all the dying. (p. 174).

might wonder what happens to notions of strength and achievement in human endeavour? Is there a risk that this notion is truncated through a fundamentalist reading of the theology of Faith and Light? Is Christian vocation simply to wash the feet of the poor? One wonders whether other legitimate expressions of Christian vocation have been surrendered in the privileged position accorded to the poor. Vanier's critique of "success" might mitigate against pursuit of excellence in other dimensions of human activity.

Community

Vanier's stance of putting the most vulnerable at the centre of community life may be necessary in the prevailing One-Third World climate of liberal individualism and the consumerist and competitive culture it has spawned. Positive discrimination (discriminating in favour of those who are marginalised) might help redress a balance. The question remains whether the stance will be sustainable and ultimately life-giving to community over the long-term. In centring community life on those with an intellectual disability, Vanier relies on his reading of a passage from the writer of the First Letter to the Corinthians, who uses the human body as a metaphor for community life. Those that seem to be weaker are described as "indispensable," and those that are thought less honourable or less respectable are to be perceived as being clothed with greater honour, or treated with greater respect (1 Cor. 12.22-24). However, the writer does not say that those who are most vulnerable are to be given central place in the life of the community. The writer states that God gives them greater honour. The greater honour is given for an express purpose: "... that there may be no dissension within the body, but the members might have the same care for one another" (1 Cor. 12.25-26). It appears that equality of care and concern for one another is the writer's principal focus. Traditional Christian ecclesiology would place Jesus Christ at the centre of the community rather than those who are most wounded or vulnerable. God in Jesus Christ chose vulnerability, and God used the kenosis of Jesus to reveal the relationality of the Trinity and of all creation. Nonetheless Jesus Christ's vulnerability is of a radically different nature to that of humanity's vulnerability. Jesus Christ while identifying himself with the vulnerable and

marginalised, also made clear that his being is not to be limited by this categorisation (Jn. 12.8).

Furthermore, in privileging the heart, it may be that Vanier is making anthropological assumptions that diminish other dimensions of the human person. Arising out of his study of Vanier's concept of the human person, Downey (1986) speaks of the heart "sublating" the intellect and the will. By this he means that not only is the heart antecedent, or ontologically prior to the intellect and will, but that the heart orders them so that they are in service of the heart. The heart is the human capacity for relationality. Therefore one's intellect, will and emotions are at the service of a relationality of a particular kind, which in turn fulfils them.[245] This theological anthropology will have implications for community life, which may need to be made more explicit. Does it privilege some dimensions of human existence, at the expense of other dimensions? Finally, it would seem that discussion of Christian community life would need to include the implications of the concept of original sin.

Summary

Vanier's thought and vision has had a significant influence on the development of Faith and Light. It has given rise to a contemporary hermeneutic that brings forth fresh insights from the Gospel and reinterprets traditional Christian doctrine. Moreover, the community of Faith and Light remains an example of radical faithfulness to the imperatives of the Gospel, achieving an ethical integrity that judges and challenges the institutional Church.

Yet, there remains a risk that in privileging a small percentage of those who are marginalised, that the Gospel message is truncated in some areas. I have argued in Chapter Two that, as Barth has stated, where one begins theology has a pronounced effect on where one ends up. Vanier's reflections appear to issue primarily out of his experience

[245] What does this relationality look like? Downey (1986) originally had recourse to the Aristotlean triad to define particular relationality as "friendship in justice and contemplation." More recently he has deployed categories deriving from an emperichoretic understanding of the Trinity. Particular relationality embodies mutuality, reciprocity and interdependence (M. D. Downey, personal communication, September 24, 2002)

in living in community with people with an intellectual disability for the past 40 years. This context seems to have afforded an hermeneutic of brokenness. This starting point has influenced Vanier's reading of Scripture and his construal of certain Christian doctrinal loci, including the doctrine of God, Christology, soteriology, vocation and ecclesiology. In this brief *theological* reflection, I have explored the relationship of some of the Faith and Light categories arising out of a hermeneutic of brokenness to Christian doctrine as traditionally conceived. Faith and Light unquestionably has an important contribution to make to the life of the Church, not only in its interpretation and delivery of pastoral care, but in its self-understanding, including its theology and spirituality. As I have submitted in Chapter Two, I underscore that Faith and Light is an extension of, rather than co-existent with, the Church. Faith and Light appears to stand in an asymmetrical relationship with the Church, even as it has enshrined its lay community status in an amendment to its Charter and Constitution in 2002. As such, the Church in its wisdom and tradition received over two thousand years, will also have significant insights to offer Faith and Light, and may assist with locating the community's teaching and practices within the broader sweep of Christian orthodoxy and orthopraxis.

Summary

This research project pursues three lines of enquiry. It sketches the features of a theological pastoral care and counselling; it gives an overview of the history, theological motifs, and spiritual practices of the Faith and Light community; and it suggests a phenomenon of perpetual parenthood with an accompanying existential dilemma of holding on and letting go as an organising concept that undergirds parents' reported experience. This chapter has laid out how each of these lines of enquiry relate to each other, by asking the question, How do theological pastoral care and counselling, Faith and Light, and perpetual parenthood inform each other? This question divided into three separate questions focussing on the relationships between two of the three areas.

First, in examining how the phenomenon of perpetual parenthood and Faith and Light might inform each other, the data revealed aspects of Faith and Light that parents valued

for themselves (mutual support and understanding, welcome, interaction and friendship) and for their offspring (recognition and use of gifts, personal growth, friendship, listening and acceptance, Christian formation). Parents expressed a desire for greater active participation of their offspring in the monthly meetings, and for opportunities to share with each other their experiences as parents. Faith and Light appears to have further resources to offer parents in the spiritual-vocational dimension of their lives: presence as a response to suffering; recovery of the contemplative dimension in their lives and the life of their family; an attitude of abandon to, or trust in, God; a re-scripting of restrictive family narratives.

Second, the chapter traced some of the outcomes of an interaction between perpetual parenthood and a theological pastoral care and counselling. The phenomenon of perpetual parenthood will allow for a more nuanced and sensitive pastoral response to parents, as it also highlights the limited application of family life cycle theories based on conventional families. A theological pastoral care and counselling offers to parents those responses listed in answering the first question, along with a specific intervention to the holding on/letting go ambivalence. It introduces relevant theories and interventions from the social sciences on an ad hoc basis that assist with a more nuanced understanding of, and response to, particular issues that parents and families of offspring with an intellectual disability encounter. Finally, it brings the theological resources and ecclesial practices of a local and visible faith community to bear on the parents' situation.

Third, I considered what Faith and Light and a theological pastoral care and counselling might have to offer one another. Faith and Light affirms the feasibility of a theological pastoral care and counselling and demonstrates how it might look in practice. In turn, a theological pastoral care and counselling will bring the full ambit of the Church's theological resources to bear upon Faith and Light, as a means of locating and assessing the theological underpinnings of its practice. I concluded the chapter with an example of how a theological critique of Faith and Light might look.

Chapter Nine

CONCLUSION

This research project grew out of a fascination with the relational dynamics embodied in a Christian residential community and a related Christian support group network centred around people with an intellectual disability. From a pastoral care and counselling perspective, it seemed to me that the manner in which L'Arche and Faith and Light embodied the Christian Gospel in their community life had implications for family functioning. I have explored this connection by eliciting from member parents of a local community what contributions Faith and Light had made in their experience to their family at the launching or transition phase. The project appeared to develop a life of its own. First, it became clear that data emerging in response to the research question divided into two distinct parts (a) the experiential world of parents as they faced launching their offspring with an intellectual disability, and (b) the role of Faith and Light as a provider of pastoral care and counselling in that context. Second, the project necessitated a re-examination of my understanding of pastoral care and counselling, and in particular the tensive relationship between theology and the social sciences, and theology and experience. What began as a growing concern that Faith and Light was not making more use of social scientific insights in its provision of pastoral care to families, gave way to an appreciation of Faith and Light's understanding of the Christian ministry of pastoral care and counselling sourced in the theological and ecclesial resources of the Church. Faith and Light's provision of care to its members made sense when the primacy of the theological and ecclesial nature of pastoral care and counselling was reasserted over a social scientific explanatory schema. Hence, what began as an exploration of the contributions of Faith and Light to families at the launching or transition phase evolved into three main foci of enquiry (a) the identity of pastoral care and counselling, (b) the

nature and the activity of Faith and Light, (c) the experience of parents of offspring with an intellectual disability around the launching or transition phase.

In the first chapter I have presented a theological pastoral care and counselling, an approach to pastoral care that retrieves its theological and ecclesial heritage. It propounds an asymmetrical relationship between theology and the social sciences, where insights from secular disciplines are annexed to the Church's own categories for its understanding and delivery of pastoral care. The focus shifted in the second chapter to the community of Faith and Light, where I traced the history, development, and some of the theological and ethical motifs of the movement. In the third chapter, I conducted a brief survey of selected social science literature relevant to the study. Theories and perspectives reviewed included family systems theory, life cycle theory, Rolland's Family Systems Illness Model, a resource-based perspective, launching phase theory, stress and coping theory, grief theory and family belief systems theory. A significant component of the research project is an ethnographic study of parents of offspring with an intellectual disability. In the fourth chapter I outlined ethnography as the qualitative methodology selected, and described the use of focus groups, participant observation and open-ended interviews to collect data. I summarised how data was reduced, coded and analysed. The findings of the ethnographic study of parents' experience were presented in a thematic schema weighted according to lines of transcript devoted to each issue in the fifth chapter. In the sixth chapter I presented an organising concept that appeared to underwrite the issues identified in the previous chapter, which I named perpetual parenthood with an associated existential ambivalence of holding on/letting go. I explored some theories sourced in a social scientific paradigm that related to the suggested phenomenon: VanKatwyk's concept of family identity located at biophysical, psychosocial and spiritual-vocational levels, Bowlby's attachment theory, Boszormenyi-Nagy's concept of relational ethics, Ricoeur's narrative theory, and recent grief theory. I compared these with a pastoral theological perspective on leaving home, which included a discussion of the role of ritual. In the seventh chapter I unpacked some of the implications of the interaction among the three principal loci of enquiry in the research project. I teased out how a theological pastoral care and counselling, the Faith and Light

community, and a phenomenon of perpetual parenthood with a holding on/letting go ambivalence might inform each other.

The study yielded several surprises. While the parents interviewed were committed members of a local Faith and Light community, they preferred to talk about their experiences with their offspring rather than about the launching phase, Faith and Light or the influence of Faith and Light on their families. I have combined the issues raised in their experiences as parents into four areas: the challenges they face as parents, particularly around the threat of abuse and the need to advocate for their offspring; their concerns over the adequacy of care their offspring receive from caregivers and health care professionals; the impact of the various transitions across the life cycle for parents and offspring alike; and parents' investment in their offspring and their peculiar knowledge of them. I have suggested that these issues are correlated to the organising concept of perpetual parenthood, fundamental to which was negotiation of the holding on/letting go ambivalence. This universal existential dilemma, where the presence of each pole vitalises the other, is one that parents return to across the life cycle of their family, rendering any resolution they discover and receive only provisional. The balance struck in the ambivalence varies from family to family.

Identification of a phenomenon of perpetual parenthood may permit the delivery of pastoral care that is more sensitive to the particular situation of parents of offspring with an intellectual disability. The phenomenon highlights the contextual nature of family life cycle theory, and the limitations of life cycle models based primarily on conventional families. That being said, these parents themselves were not interested in a sophisticated discussion of relational dynamics operative in the family at the launching phase. My desire to establish a link between the launching phase in these families and Faith and Light failed. Yet, parents spoke in positive terms about Faith and Light as a community that is unashamed to bring the *resources of the Christian faith* to the pastoral needs of its members. What they appeared to find helpful was not social scientific theory associated with what they were living; rather they appreciated the practices of the Church. Their reported experience offers a fresh angle on pastoral care and counselling. What Faith and

Light may offer the Church is a bolstering of the Church's confidence in its own wisdom and tradition in the provision of pastoral care and counselling. There is a sense in which the reported experience of parents invites the Church to be the Church. I reiterate that it does not mean a wholesale rejection of insights from secular fields of knowledge. Rather the pastoral carer appeals to related secular disciplines on the basis of the grammar of faith.

Admittedly, Faith and Light could allow the pastoral care it extends to be massaged or nuanced by the particular needs of parents as identified in the research. It may need to ask itself how it can facilitate the location of these identified issues within the Christian metanarrative in such a way that God's light and salvation touches these specific areas. Perhaps it entails using specific accounts from the life and teachings of Jesus that speak to the thoughts and feelings that parents have expressed. Parents themselves expressed a desire for greater active participation of their offspring in the monthly meetings, and for opportunities to share with each other their experiences as parents. Faith and Light could promote small groups for parents within or outside the context of the monthly meeting with facilitated discussion around issues that parents are living. It could encourage links with family networks and other resources available to parents, such as PLAN.[246] It may need to provide a space within which parents can pray and be prayed for, and to promote actively supportive friendships amongst parents living different realities, encouraging informal contact outside meetings. In its monthly meetings, the community might lift up and celebrate those aspects that bring parents joy, as well as sharing with parents in their challenges. It could promote those attributes of community life parents reported as being helpful for themselves (mutual support and understanding, interaction, welcome and friendship), and for their offspring (revealing their beauty and giftedness, growth and friendship, Christian formation, listening and acceptance).

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[246] PLAN (Planned Lifetime Advocacy Network) is a not-for-profit community, formed in 1988 in British Columbia, Canada that aims to assist families with offspring with a disability in developing a future-care plan for their offspring, establish resources for funding, and identify both people and programmes able to help with implementing the plan. It also advocates with governmental and non-governmental agencies for people with a disability, and lobbies for reform of tax and trust legislation. For further information, see Etmanski (2000) and http://www.plan.ca/about/index.htm.

In a cursory critique of the theology undergirding Faith and Light, some questions did emerge, indicating the need for the organisation to be closely referenced to orthodox Christian theology and Church practice. Nonetheless, it seemed that the benefits emanating from the life of Faith and Light far outweighed any perceived or anticipated detriments. While some theological questions remain and some adjustments were suggested at the local level, the pastoral care that Faith and Light holds out to its members has much to commend it. Indeed, one wonders what Faith and Light might hold out as a paradigm for pastoral care and counselling in other settings. Might the format of gathering together, listening to and enacting Scripture, reflecting in small groups and engaging in simple activities, praying together and singing, and sharing a simple meal together assist people, who are for example frozen in grief over the sudden death of an infant? Is the ministry of word and sacrament as pastoral care that Faith and Light lives and shares, a model for the provision of pastoral care in other contexts? The findings bear witness to the capacity of Christian community founded on word and sacrament to extend care, to bring healing and to generate transformation in the lives of its members through its shared life together.

Limitations of the Research

There are a number of limitations inherent in this research. First, having a passion for, and a strong interest in both pastoral care and counselling and Faith and Light, I may be predisposed toward looking for and "seeing" instances of pastoral care in Faith and Light, which other researchers might not recognise. I have conducted the research from an explicitly Christian perspective. Second, empirical studies of families with members with an intellectual disability collect organized units of measurable data and apply statistical tests which confirm or refute the hypothesis. This research project used qualitative research, where I began with a question to be explored rather than a hypothesis to be tested. This project has not purported to test a theoretical model. The questions were designed to elicit participants' experience rather than to verify constructs contained in a theory. The research project risks therefore a lack of coherence and interconnectedness it might otherwise have if wedded to a theory. The traditional yardsticks of reliability and

validity in research methodology are also more difficult to apply in qualitative research. While I have outlined in Chapter Four the measures employed to promote reliability and validity at various stages of the research process, it is obvious that ethnographic research is highly interpretive, and will reflect researcher bias. Furthermore, interpretation entails judgment. The process of selection of some data necessitates omission of other data. There may remain important insights in data that was not used. Third, I chose to begin with a brief survey of the literature in order to familiarize myself with the history and the culture of Faith and Light, and with a systemic and developmental understanding of families with members with an intellectual disability. I hoped that this would provide a deeper understanding of Faith and Light and of the participant families, and allow me thus to be more sensitive to the families' realities and to pose more relevant and helpful questions. The downside of this process is that my reading of the existing theory will have invariably shaped the way in which I collected, reduced and analysed the participants' stories. Beginning with the participants' stories may have yielded insights that I was not predisposed to look for by reason of familiarity with relevant social science theory. Fourth, intellectual disability, family systems and life cycle research are all fields that cross a number of disciplines (eg. family systems theory, pastoral care and counselling, social psychology, clinical psychology, family sociology, disability research, and education). The published material in these areas in any one discipline is vast. It is unlikely that a researcher would uncover all the relevant material in one discipline, let alone in every related discipline. There exists a discontinuity of research findings across the various disciplines. In addition, the body of writing surrounding intellectual disability and the family reveals a wide variety of interested parties: theorists, researchers, clinicians, service providers, and families themselves. There is a risk that each group uses different language, with an associated lack of understanding and communication between the various players. There appears to be a lack of precision in definitions making it difficult to ascertain whether writers are discussing the same phenomena (eg. "family," "intellectual disability," "launching," "transition;" Turnbull et al., 1993, pp. 5-8). It need be added that none of the literature consulted addressed directly the guiding question of this research project. Fifth, not only were the parents selected all Christian, they were all active members of the Roman Catholic Church. Their religious heritage will influence

their perception of the issues they reported, as will my own Christian faith in interpreting the data. In the first two focus groups, parents' ages ranged from 69 to 79; Kevin (65) and Frances (60) joined the third group. The experience of parents outside this age range will probably reveal other issues. It will be remembered that the sample size is very small. Participants were all members of the same local Faith and Light community. There may be differences in how other Faith and Light communities give expression to their corporate life and in the care they extend to members. While qualitative researchers concern themselves not with the generalisability of their data or their findings but with the generalisability of their theory, for the reasons stated above, I advance tentatively the theoretical implications of the research.

Directions for Future Research

I conclude by offering some suggested areas for further research. First, I have laid out merely a preliminary outline of a theological pastoral care and counselling. There remains significant work not only in defining further the theology and the social science theory underwriting it, but in teasing out what this approach might look like in practice, particularly in contexts other than the Faith and Light community. Second, the recognition of Faith and Light as a provider of pastoral care and counselling to its members was an insight that arose in the course of this research project. It might benefit both the community of Faith and Light and the field of pastoral care and counselling to conduct further research on the ways in which Faith and Light delivers pastoral care to its members and how the provision of such care is perceived and received by its members. Finally, I have proposed tentatively the phenomenon of perpetual parenthood with its accompanying ambivalence of holding on and letting go as an organising concept that might underlie some of the issues that parents of offspring with an intellectual disability face. A further step in exploring further the concept would entail operationalising the variables in the qualitative findings and testing them statistically with a larger and more varied sample.

Appendix A

Foundational Scriptural Texts for the Spirituality of Faith and Light[247]

God's Chooses Vulnerability and Reveals Godself in Vulnerability

> ...But God chose what is foolish in the world to shame the wise; God chose what is weak in the world to shame the strong; God chose what is low and despised in the world, things that are not, to reduce to nothing things that are... (1 Cor. 1.26-29).
> Three times I appealed to the Lord about this, that it would leave me, but he said to me, "My grace is sufficient for you, for my power is made perfect in weakness." So I will boast all the more gladly of my weaknesses, so that the power of Christ may dwell in me... ; for whenever I am weak, then I am strong (2 Cor. 12.8-10).
> At that time Jesus said, "I thank you, Father, Lord of heaven and earth, because you have hidden these things from the wise and the intelligent and have revealed them to infants" (Mt. 11.25; see also Lk. 10.21).

God is Incarnate in Jesus Christ

> In the beginning was the Word, and the Word was with God, and the Word was God. He was in the beginning with God. All things came into being through him... And the Word became flesh and lived among us... (Jn. 1.1-3, 14)

Jesus Becomes Vulnerable and Identifies Himself with the Vulnerable

Jesus' birth (Mt. 1.18-25; Lk. 2.1-20).
Jesus' agony in the Garden of Gethsemane and his passion.
"...Whoever welcomes one such child in my name welcomes me..." (Mk. 9.33-37; see also Mt. 18.1-5; Lk. 9.46-48).
"...Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me" (Mt. 25.31-46).

The Mission to Care for the Vulnerable

"...I am the good shepherd..." (Jn. 10.1-18)
"Is this not the fast that I choose...?" (Is. 58.6-7).
"The Spirit of the Lord is upon me, because he has anointed me to bring good news to the poor..." (Lk. 4.18-19).

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[247] See also the foundational biblical texts for the spirituality of Faith and Light selected by the International Chaplain Fr. Joseph Larsen that appear in *Morning and evening prayers: suggestions for their preparation* (1997, p. 26). The subcategories Fr. Larsen identifies are: concern about the poor; God has chosen the poor; to become like little children; Jesus identifying himself with the poor; Jesus becomes poor; the Beatitude of being with the poor; community life; the promise of the Holy Spirit; and the Good Shepherd.

"He said, 'The one who showed him mercy.'Jesus said to him, 'Go and do likewise.'" The parable of the Good Samaritan (Lk. 10.25-37).

> On the contrary, the members of the body that seem to be weaker are indispensable, and those members of the body that we think are less honourable we clothe with greater honour, and our less respectable members are treated with greater respect;... (1 Cor. 12. 22-23).

The Mission to Enter into Communion with the Vulnerable (Sharing at Table, Befriending)

"...Truly I tell you, whoever does not receive the kingdom of God as a little child will never enter it" (Mk. 10.13-16).
"...But when you give a banquet, invite the poor, the crippled, the lame, and the blind. And you will be blessed because they cannot repay you..." (Lk. 14.12-14)
The parable of the marriage feast or great supper (Mt. 22.1-14; Lk. 14.16-24)

The Mission to Reconcile Different Groups of People

> For he is our peace; in his flesh he has made both groups into one and has broken down the dividing wall, that is the hostility between us. He has abolished the law with its commandments and ordinances, that he might create in himself one new humanity in place of the two, thus making peace, and might reconcile both groups to God in one body through the cross, thus putting to death that hostility through it (Eph. 2.14-16).

"Blessed are the peacemakers, for they will be called the children of God..." (Mt. 5.9).

Shared Love and Communion Expressing Itself in Community Life

"You are my Son, the Beloved; with you I am well pleased" (Mk. 3.11; see also Mt. 3.17; Lk. 3.22).
"...By this everyone will know that you are my disciples, if you have love one for another" (Jn. 13.34-35).

> As the Father has loved me, so I have loved you; abide in my love. If you keep my commandments, you will abide in my love, just as I have kept my Father's commandments and abide in his love. I have said these things to you so that my joy may be in you, and that your joy may be complete. This is my commandment, that you love one another as I have loved you (Jn. 14.9-12).

"This is my commandment, that you love one another as I have loved you..." (Jn. 15.12-17).
"...be of the same mind, having the same love, being in full accord and of one mind" (Phil. 2.1-5).
The first Christian communities (Acts 2.42-45; 4.32-34).
"...Above all, clothe yourselves with love, which binds everything together in perfect unity..."(Col. 3.12-17).
"Beloved, let us love one another, because love is from God; everyone who loves is born of God and knows God" (1 Jn. 4.7).

Love as Humble Service of One Another

> ... So if I, your Lord and Teacher, have washed your feet, you also ought to wash one another's feet... If you know these things, you are blessed if you do them... (Jn. 13.14,17). Jesus washes the disciples' feet (Jn. 13.1-20).

"... but emptied himself, taking the form of a slave... he humbled himself..." (Phil. 2. 6-11).

Presence to One Another in Suffering

> Be merciful, just as your Father is merciful. Do not judge, and you will not be judged; do not condemn, and you will not be condemned. Forgive and you will be forgiven; give and it will be given to you (Lk. 6.36-37).
>
> He called the crowd with his disciples, and said to them, "If any want to become my followers, let them deny themselves and take up their cross and follow me. For those who want to save their life will lose it, and those who lose their life for my sake, and for the sake of the Gospel will save it" (Mk. 8.34-35; see also Mt. 16.24-25; Lk. 9.23-24).

Mary remaining with Jesus at the foot of the cross (Jn. 19.25f.).

The Promise of the Holy Spirit

"A new heart I will give you, and a new spirit I will put within you; and I will remove from your body the heart of stone and give you a heart of flesh..." (Ezek. 36. 26-27).
"...And I will ask the Father, and he will give you another Advocate, to be with you forever..." (Jn. 14.15-30).
"...for if I do not go away, the Advocate will not come to you; but if I go, I will send him to you..." (Jn. 16.7-14).

Others

> He came to what was his own, and his own people did not accept him. But to all who received him, who believed in his name, he gave power to become children of God... (Jn. 1.12).

Ezekiel's vision of water flowing from the Temple (as a metaphor for the nourishment received from the Church) (Ezek. 47)

> His disciples asked him, "Rabbi, who sinned this man, or his parents that he was born blind?" Jesus answered, "Neither this man nor his parents sinned; he was born blind so that God's works might be revealed in him" (Jn. 9. 2-3).

Texts Cited by Jean Vanier in an address entitled "The Mission of Faith and Light" at the Faith and Light International General Meeting in September 2002 in Rome.

Healing and reconciliation
Eph. 2.14; "Blessed are the peacemakers…"

Poor are Jesus
Mt. 25

Community
1 Jn. 4.1-7

Friendship with the poor
Lk. 14. 12-14

Service
Jn. 13

Most vulnerable at the heart of community life
1 Cor. 12

Appendix B

The Faith and Light Prayer

Jesus, you came into our world,
To reveal the Father to us, your Father and our Father.
You came to teach us to love one another.
Give us the Holy Spirit, according to your promise,
So that he will make us instruments of peace and unity,
In this world of war and division.

Jesus you have called us to follow you
In a community of Faith and Light.
We want to say "Yes" to you.
We want to live in a covenant of love
In this big family you have given us,
Where we can share our sufferings and difficulties,
Our joys and our hope.
Teach us to accept our wounds, our weakness
So that your power may be revealed.
Teach us to find you in all our brothers and sisters,
Especially in those who are weakest.
Teach us to follow you in the way of the Gospel.
Jesus, come and live in us and in our communities
As you first lived in Mary
She was the first to welcome you in herself.
Help us to welcome you into our hearts and in our communities.
Help us to be always standing with her, at the foot of the cross,
Near the crucified of the world.
Help us to live Your resurrection.
Amen.

Appendix C

Faith and Light – A Ceremony of the Washing of Feet

THE GATHERING OF THE COMMUNITY

Opening song and welcome

Celebrant The grace of our Lord Jesus Christ,
and the love of God,
and the fellowship of the Holy Spirit,
be with you all.
All ***And also with you.***

Celebrant 'Now before the festival of the Passover, Jesus knew that his hour had come to depart from this world and go to the Father. Having loved his own who were in the world, he loved them to the end' (Jn. 13.1).

Confession and absolution

Leader For all the suffering and pain that indifference, resentment and prejudice has caused in this corner of the universe.
All ***Lord we are sorry***

Leader For the pride which has prevented forgiveness and understanding.
All ***Lord we are sorry***

Leader For the times we were blind and failed to see the beauty in the other,
for the times we were deaf and failed to listen to the other,
for the times we were dumb and failed to talk with the other.
All ***Lord we are sorry***

Celebrant Almighty God have mercy upon us,
pardon and deliver us from all our sins,
confirm and strengthen us in all goodness
and keep us in eternal life;
through Jesus Christ our Lord. ***Amen***

Song

Prayer of the day

Celebrant All powerful and ever-loving God,
whose Son Jesus Christ took a towel and washed his disciples' feet,
setting us an example that he commands us to follow.
Give us grace to love others as you love us,
by serving one another in tenderness and humility,
through Jesus Christ our Lord,
who lives and reigns with you and the Holy Spirit,
one God, now and forever. ***Amen.***

THE PROCLAMATION OF THE WORD

The readings

Old Testament reading	Isaiah 58. 6-12
Psalm	Psalm 46
Response (sung)	***Be still and know that I am God***
Epistle reading	Ephesians 2. 14-18
Gospel acclamation	
Gospel (drama)	John 13. 1-17

Homily

Renewal of baptismal vows

Celebrant Dear friends,
in our baptism we died with Christ and were buried with him
so that we might rise with him to new life within the family of his church.
Today we renew the promises made at our baptism,
affirm our allegiance to Christ
and our rejection of all that is evil.

Celebrant Do you reaffirm your renunciation of evil
and renew your commitment to Jesus Christ?
All ***I do***

Celebrant Do you believe in God the Father?
All ***I believe in God,***
The Father Almighty,
Creator of heaven and earth.

Celebrant Do you believe in Jesus Christ, the Son of God?
I believe in Jesus Christ,
his only son, our Lord.
He was conceived by the power of the Holy Spirit

and born of the Virgin Mary.
He suffered under Pontius Pilate,
was crucified, died, and was buried.
He descended to the dead.
On the third day he rose again.
He ascended into heaven,
and is seated at the right hand of the Father.
He will come again
to judge the living and the dead.

Celebrant Do you believe in God the Holy Spirit?
All ***I believe in the Holy Spirit,***
the holy catholic Church,
the communion of saints,
the forgiveness of sins,
the resurrection of the body,
and the life everlasting.

Celebrant Will you continue in the apostles' teaching and fellowship, in the breaking of bread, and in the prayers?
All ***I will, with God's help.***

Celebrant Will you persevere in resisting evil and whenever you fall into sin, repent and return to the Lord?
All ***I will, with God's help.***

Celebrant Will you proclaim by word and example the good news of God in Christ?
All ***I will, with God's help.***

Celebrant Will you seek and serve Christ in all persons, loving your neighbour as yourself?
All ***I will, with God's help.***

Celebrant Will you strive for justice and peace among all people, and respect the dignity of every human being?
All ***I will, with God's help.***

Celebrant God has given us new birth by water and the Holy Spirit,
and bestowed upon us the forgiveness of sins,
through our Lord Jesus Christ.
May God in the tenderness and humility of his Son
who kneels before us and washes our feet,
keep us faithful to our calling,
now and forever. Amen.

The peace

Celebrant The peace of the Lord be always with you
All ***And also with you.***

Song

THE WASHING OF FEET

Prayer before washing of feet

Celebrant All powerful and ever-living God,
we do well always and everywhere to give you thanks,
through Jesus Christ our Lord.
You sent your Son to live among us,
so that we might learn from him humility and obedience.
His nature was divine yet he did not cling to his equality with God
but emptied himself to assume the condition of a slave.
He became as we are, humbling himself further,
and accepting death, even death on a cross.
But you, O God, raised him on high,
and gave him the name which is above all names,
so that we can acclaim
JESUS IS LORD
to your honour and glory,
and join with the whole company of heaven and earth, singing,

All ***Holy, holy, holy Lord,***
God of power and might
Heaven and earth are full of your glory.
Hosanna in the highest.
Blessed is he who comes in the name of the Lord.
Hosanna in the highest.

Celebrant All powerful and ever-loving God,
we thank you for the great gift of Jesus,
for his promise to be with those who love and follow him.
Having loved his own, he loved them to the end.
On the night before he gave his life for us,
knowing that you had put everything into his hands,
Jesus met with his disciples and gave them his new commandment,
'Love one another as I have loved you.'

On the same night,
Jesus raised his eyes to heaven and prayed to you, saying:
'May they all be one. As you, Father, are in me and I am in you, may they also be in us, so that the world may believe that you have sent me.'
As we remember Jesus, his life, his love even unto death,
his desire for our unity in his love,
and his resurrection,
we rejoice that he has given us his Spirit
to be his hands and his body now in the world.
May the Holy Spirit create in us,
the mind that was in Christ Jesus
to enable us to love and live as he did,
without counting the cost,
to desire a unity in love as he did
without losing heart.

Getting up from the table, he took a towel and water,
washed his disciples' feet, and said,
'I have given you an example.
You are to do for one another what I have done for you.'
May the Holy Spirit reveal to us
the presence of Jesus in the poorest and the weakest.
May we listen to them, receive their gifts
and be led into a healing covenant with them
and through them with each other.

All ***All powerful and ever-loving God***
Heal the broken body of humanity,
the broken body of your Church.
It is true that today we cannot all eat
around the same table of the broken bread,
transformed into the body of Christ.
But we can eat together around the same table
with the poor and the weak.
It is true that today we cannot drink
from the same chalice of the blood of Christ.
But we can all drink together from the same chalice of suffering:
the suffering of division, of brokenness in our country and in our world.
Together we can pour out the sweet oil of compassion
upon the wounds of humanity:

We pray that unity will come,
not only around the treasure of the body of Jesus,
his broken, risen body which we know in the Eucharist,
but also through the treasure of the broken body of Jesus
we know in the poor.

We know that the Eucharist,
and the washing of the feet of wounded people,
the broken body of Christ,
bring unity in love and your presence in our brokenness.

Celebrant Father, for all this we give you thanks
through Jesus Christ your Son,
who lives and reigns with you and the Holy Spirit,
one God, for ever and ever. ***Amen.***

Washing of feet

Prayers of the people

(People are free to offer their own intentions spoken aloud or offered in silence. The sung response is ***O Lord, hear my prayer*** . The celebrant concludes the prayers by leading the congregation in The Lord's Prayer).

Blessing and dismissal

Celebrant God the Father,
God in whom we live and move and have our being,
God who is love:
You are the One who welcomes us back into your embrace,
'merciful and gracious, slow to anger,
abounding in steadfast love and faithfulness.'
Deepen our awareness that our hearts are restless,
and that they will not rest until they rest in you. ***Amen***

God the Son, Word made flesh,
Jesus our Saviour, God-with-us:
You are the Alpha and the Omega,
the beginning and the end,
the first and the last.
Yet you came not to be served, but to serve.
Guide us in your way of service,
the way of the washing of the feet,
the way of the Cross,
that together with all Christians,
we may grow more fully into a communion of love and service. ***Amen.***

God the Holy Spirit, Comforter, Advocate,
Spirit not of slaves
but of the sons and daughters of God:
You are our consolation,

God's love poured into our hearts,
coming to help us in our weakness.
Bless us with your fruits –
love, joy, peace, patience, kindness,
goodness, trustfulness, gentleness and self-control –
so that we may be salt of the earth and light for the world. ***Amen.***

And may the blessing of Almighty God,
Father, Son and Holy Spirit
Come down and remain with you for ever. ***Amen.***

Leader Go in peace to love and serve the Lord.
All ***Thanks be to God.***

Closing song

Appendix D

University Research Ethics Committee Letter

Wilfrid Laurier University

Founded 1911

April 23, 2002

Tim Dobbin
Waterloo Lutheran Seminary
Wilfrid Laurier University

Dear Mr. Dobbin:

Re: Your Research Proposal Entitled, "The experience of gift and challenge at different stages of the family life cycle in families with children with developmental disabilities"

The Research Ethics Board of Wilfrid Laurier University has reviewed the above proposal and determined that the proposal is ethically sound.

If the research plan and methods should change in a way that may bring into question the project's adherence to acceptable ethical norms, please contact me as soon as possible and before the changes are put into place.

Upon completion of your research project, you must submit a final report. You can use the "Final Report on Graduate Student Projects", found on the Research Office web site (http://www.wlu.ca/~wwwroff/humanethics.shtml), as a template.

Yours sincerely,

Bill Marr

B. Marr, PhD
Chair, WLU Research Ethics Board

BM/jb

Cc: P. VanKatywk

Appendix E

Information Letter

WILFRID LAURIER UNIVERSITY

INFORMATION LETTER

[The contributions of Faith and Light to families with offspring with an intellectual disability at transition or the school-leaving stage]

Focus group

Principal investigator: Tim Dobbin
Advisor: Peter VanKatywk, PhD
Professor of Pastoral Care and Counselling, WLU

You are invited to participate in a research study. The purpose of this study is to discover your experience of the contributions of Faith and Light to your family life at transition or the school-leaving stage. *Tim Dobbin is a full-time student in the Doctor of Ministry in pastoral counselling and marriage and family studies programme at Waterloo Lutheran Seminary, a federated college of Wilfrid Laurier University.*

INFORMATION

You are being asked to participate in a discussion on your experience of the contributions of Faith and Light to your family life at transition or the school-leaving stage. The investigator will ask a number of questions which are enclosed. You do not have to answer all the questions and can decline to participate further in the focus group at any time. Your choice to discontinue participation in the focus group will have no consequences for other members of your family who may be involved in the project. The discussion will be audio-taped and should last no longer than 1-1.5 hours. The discussion

will then be transcribed. Any identifying features such as your name, the names of other persons, places, third parties etc. from the transcript will be removed. After transcription, you will have the opportunity to edit your own statements in the discussion. The sample size for this research is 8-10 participants. There will be one focus group consisting of parents. The focus group may meet several times. The investigator will present the findings in a dissertation to be submitted in partial fulfilment of the requirements of the Doctor of Ministry degree. The investigator may also make use of the findings in other publications or presentations. Any quotations that appear in the dissertation or any other publications or presentations will not have the participant's name or any other identifying features. After the research is completed, a summary of the findings will be available for participants to review if they wish to.

RISKS

There are no major risks in this research. There is the possibility that you might disclose personal information that leaves you feeling uncomfortable. You have the right to decline to participate further in the discussion at any time. The investigator will offer support, and if appropriate make referral to an appropriate professional.

BENEFITS

You might find it helpful to discuss your experience of gift and challenge at various stages in the life cycle of your family. This research might help other families in reflecting upon and understanding their experiences of gift and challenge. This research might contribute to the body of knowledge concerned with family functioning in families with children with a developmental disability.

CONFIDENTIALITY

Everything you discuss is confidential. Each member of the group will be required to agree to confidentiality concerning who is in the group and what is shared in the group.

While the investigator will take appropriate steps to ensure confidentiality, it is important to note that in a focus group setting confidentiality cannot be guaranteed. In your answer to the questions, confidentiality will be protected by removing your name from the transcripts and replacing it with a number. Any identifying features such as names of other persons, places, third parties etc. will be removed from the transcript. Only the investigator will have access to all the data. The audio-tapes will be erased after transcription. The audio-tapes and the transcribed interviews will be kept in a locked filing cabinet at the investigator's home office. After the project is finished, the transcribed interviews will be destroyed.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Tim Dobbin , at St. George's Anglican Church, 227 Wharncliffe Rd North, London and (519) 438-2994. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. You have the right to omit any question(s) you choose.

Appendix F

Informed Consent Statement

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

[The contributions of Faith and Light to families with offspring with an intellectual disability at transition or the school-leaving stage]

Focus group

Principal investigator: Tim Dobbin
Advisor: Peter VanKatywk, PhD
Professor of Pastoral Care and Counselling, WLU

You are invited to participate in a research study. The purpose of this study is to discover your experience of the contributions of Faith and Light to your family life at transition or the school-leaving stage. *Tim Dobbin is a full-time student in the Doctor of Ministry in pastoral counselling and marriage and family studies programme at Waterloo Lutheran Seminary, a federated college of Wilfrid Laurier University.*

INFORMATION

You are being asked to participate in a discussion on your experience of the contributions of Faith and Light to your family life at transition or the school-leaving stage. The investigator will ask a number of questions which are enclosed. You do not have to answer all the questions and can decline to participate further in the focus group at any time. Your choice to discontinue participation in the focus group will have no consequences for other members of your family who may be involved in the project. The discussion will be audio-taped and should last no longer than 1-1.5 hours. The discussion

will then be transcribed. Any identifying features such as your name, the names of other persons, places, third parties etc. from the transcript will be removed. After transcription, you will have the opportunity to edit your own statements in the discussion. The sample size for this research is 8-10 participants. There will be one focus group consisting of parents. The focus group may meet several times. The investigator will present the findings in a dissertation to be submitted in partial fulfilment of the requirements of the Doctor of Ministry degree. The investigator may also make use of the findings in other publications or presentations. Any quotations that appear in the dissertation or any other publications or presentations will not have the participant's name or any other identifying features. After the research is completed, a summary of the findings will be available for participants to review if they wish to.

RISKS

There are no major risks in this research. There is the possibility that you might disclose personal information that leaves you feeling uncomfortable. You have the right to decline to participate further in the discussion at any time. The investigator will offer support, and if appropriate make referral to an appropriate professional.

BENEFITS

You might find it helpful to discuss your experience of what Faith and Light offered the life of your family at the school-leaving stage. This research might help other families in reflecting upon and understanding their experiences of Faith and Light. This research might contribute to the body of knowledge concerned with family functioning in families with offspring with an intellectual disability.

CONFIDENTIALITY

Everything you discuss is confidential. Each member of the group will be required to agree to confidentiality concerning who is in the group and what is shared in the group.

While the investigator will take appropriate steps to ensure confidentiality, it is important to note that in a focus group setting confidentiality cannot be guaranteed. In your answer to the questions, confidentiality will be protected by removing your name from the transcripts and replacing it with a number. Any identifying features such as names of other persons, places, third parties etc. will be removed from the transcript. Only the investigator will have access to all the data. The audio-tapes will be erased after transcription. The audio-tapes and the transcribed interviews will be kept in a locked filing cabinet at the investigator's home office. After the project is finished, the transcribed interviews will be destroyed.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Tim Dobbin , at St. George's Anglican Church, 227 Wharncliffe Rd North, London and (519) 438-2994. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. You have the right to omit any question(s) you choose.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Subject's signature_____ Date _____

Investigator's signature_____ Date _____

Appendix G

Introduction to the First Focus Group

Good morning and welcome. Thanks very much for making the time to be part of the discussion on Faith and Light and its influence on your family. You all know me. Anne Escrader is assisting me this morning (introduce Anne).

I invited you because you are all parents of adults with intellectual disabilities and you are all active members of Faith and Light. I would like to explore your experiences, your thoughts and feelings on being a parent, particularly at the launching phase (when your child is approaching the "leaving home" age). I am interested especially in the influence of Faith and Light on your family life.

I am not a parent, let alone a parent with a child with an intellectual disability. I am here to learn from you. There are no right and wrong answers. We expect that you will have different experiences and different points of view. I am interested in as many different perspectives as are possible. Even if your experience differs only a little bit from someone else's please mention it. It is exactly what I want to hear. Often we find that others remember they have had similar experiences, and it starts a whole new direction of discussion. I am also interested in hearing as many stories as possible. Even if your experience sounds similar to someone else's, rather than simply say "I agree," please feel free to share your own story, because everyone's story is personal and it is unique. We are just as interested in what was difficult, or what has not helped, as we are in what has been great, or what has helped. Sometimes reflections that point out what is not working are the most helpful.

We are tape recording the session to make sure we get all of your comments. As I have stated in the information letter, I will be changing any identifying characteristics including your names and other personal details. I re-iterate that our discussion remains confidential, and would ask you to respect the confidentiality of others when we leave.

It probably works best having one person speaking at a time, without any side conversations with your neighbours. If you want to follow up on what someone has said, whether to agree or disagree, feel free to do so. Please feel free to enter into discussion with each other. There is no need to direct conversation through me. My job is to ask questions, to listen and to make sure that everyone has an opportunity to share. If someone does get off topic, we usually find that someone else brings the discussion back on track. I will jump in if I need to. Generally we have found that someone takes care of that for us. If you see that someone else has not joined in, or you notice you are hearing from the same people, try asking a question of someone who is not saying much. One of the reasons we ask general questions at the start is so that you can use that information to ask questions of people later on. If you think that you are running out of things to say, know that I am interested in hearing as many different things as possible.

Please feel free to help yourself to refreshments or to use the bathroom if you need to. Let's begin. I wonder if we start by sharing briefly how long we have been involved with Faith and Light, and how we found out about it.

Appendix H

First Focus Group Questions

Research question: What are the contributions of Faith and Light to families with offspring with an intellectual disability at the launching or transition phase?

Opening

How long have you been involved with Faith and Light? Where were you when your family was at the launching phase with your offspring with a disability?

Introductory

How did you first learn about Faith and Light?

Which members of your family participate in FL?

Does their participation in FL cause any difficulties in your family life?

How do you address these difficulties?

Transition

Think back to when your offspring with disabilities approached school-leaving age, and you needed to make decisions about living arrangements, employment options, and leisure activities? What were some of your issues?

How did you address some of those issues?

Key questions

In what ways did Faith and Light help you with the issues you were dealing with?

In what ways did Faith and Light not help you with these issues?

Is your family life different now because of your involvement with Faith and Light? In what ways?

Has it changed your view of yourself? Your offspring? Your family? Human nature? Relationships? The world? God?

Has it changed your relationships within and outside the family?

Any other changes? Spiritual growth?

Are the lives of your offspring different now because of their involvement with Faith and Light? In what ways?

Has it changed their view?

Has it changed their relationships within and outside families?

Any other changes? Spiritual growth?

Ending questions

If you were able to offer advice to the founders of Faith and Light, what advice would you give? To parents of offspring with an intellectual disability at the launching phase?

We wanted you to help us look at what influence Faith and Light has on families, particularly at the launching or transition stage. We want to know how Faith and Light could be more helpful for offspring and for families. Is there anything that we missed? Is there anything that you came wanting to say that you did not get a chance to say?

Appendix I

Emerging Themes from the First Focus Group

Parents

Parents with offspring with an intellectual disability learn patience

"One day at a time…"

Depth of investment of parents in offspring with a disability

Always thinking, dreaming about them even after offspring leave home

Need to protect them

"He/she is part of me"

Loss of life purpose without them

Pain associated with separation/leaving home phase

Worry, concern for offspring

Difficulty in trusting others to care adequately for offspring

Shortcomings, painful experiences with some staff in group homes, residential facilities

Difficulties that offspring with an intellectual disability experience with change in staff

Process of learning to trust

Other caregivers have different gifts to offer offspring

Need for homes to adapt to offspring with an intellectual disability rather than expecting offspring to adapt to house rhythm

Faith and Light

Community for people with an intellectual disability

- Friendship
- Lack of judgment
- Allows beauty, gifts of people with an intellectual disability to emerge
- Space for offspring with an intellectual disability to use their gifts in natural way

Community for parents

- Sense of belonging
- Expectation to be there
- Interaction, sharing with other parents
- "rubbing shoulders"
- Support

Positive aspects

- Open structure
- Shared meal
- Meeting in one room
- Regular meetings
- Easy-going, permissive atmosphere

Spiritual formation, religious education for offspring with an intellectual disability

- Importance of mime, singing

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